

Enhancing survival and quality of life for people living with GIST

February 2022

Partners Fovever Support Along the GIST Journey

By Carolyn Tordella, Director, Communications

This February, we want to focus on many kinds of love - romantic love, enduring love that supports for a lifetime (Kay and Ira Stolzer, cover), love and care for one's self ("Love, Actually", page 18) and gratefulness for those who give to those in need, regardless of their own circumstances ("What Being a GIST Mentor Means", page 3).

Our feature story is about a couple who have supported each other throughout their marriage and GIST journey. They have graciously shared how that has worked for them, and our hope is that this gives insight to others on a similar journey.



Ira & Kay Stolzer, our cover story

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From the Desk of our Executive Director

Acts of caring and kindness are the key to GIST cancer survival and happiness. I grew up in a tenement in the Bronx. We were a little crowded. My parents, European immigrants like most on our block, had a one-bedroom apartment. My grandfather, Zaide (Yiddish for grandfather) and I shared that small bedroom with barely enough room between our beds to walk out.

My younger sister slept in the living room on a fold-up bed that would be taken down during the day. Six tenement buildings on our block formed our neighborhood, along with a luncheonette and a juke box place. I will leave it to older readers to explain to the younger generation what a juke box is. I guess we were officially poor, but nobody bothered to tell us that. We did not have much, but we did have each other.

My grandfather came to this country as a young man to work with a goal to earn enough money to bring his wife and daughters to America. Unfortunately, World War I broke out just after his arrival and it would be several years before the family would be reunited. My grandfather worked very hard delivering ice on the Lower East Side in a horse-drawn carriage for people's iceboxes (no refrigerators yet) and also coal in the winter for their stoves. Zaide did not know his birthdate. He was too busy trying to survive and by the time he tried to access his records his Russian town hall had been destroyed in the war.

While still little children, my sister and I decided to give my grandfather a very special present. I remember we went to him in the living room and said, "Zaide, we have a very special present for you." As we had nothing in our hands, he looked perplexed.

"We are going to give you a birthday, February 14, Valentine's Day." That very day was St. Valentine's so we brought out a small, chocolate birthday cake and sang 'Happy Birthday' to our grandfather. It was the first time anyone had sung that song for him.

It is just such a simple act of kindness and caring that has carried over from the tenements of the Bronx to the countless global homes of our Life Raft Group survivors.

From our beginning twenty years ago, word would go out to the newly diagnosed, frightened over whether or not they were going to survive and to those far along into this strange, rare cancer journey, that "You are not alone."

Like the gift of a birthday to a grandfather, The Life Raft Group shares our gifts with our community and will continue to do so. We listen to your fears and concerns, we create resources to guide you on your GIST journey, we share your stories of hope with other GISTers. We don't do this alone, but we do it with the support of our medical specialists, collaborative partners, and researchers. *Remember you are not alone.*

- Norman J. Scherzer

What It Means To Be A GIST Mentor



By Santy DiSabatino

U.S. GIST Mentor Director for the Life Raft Group



GISTMENTOR



When I was first diagnosed with GIST it was as if my life stood still. I never expected I would get cancer. My parents lived well into their 90's. It was the way I was told by a physician at the time that also alarmed me. There was no "bedside" manner. I called my wife after I Googled "What is a GIST?" and told her. But something was still missing. I so wanted to speak with someone who shared the first shock of finding out to hopefully help me relieve some of my stress. I wasn't looking for a doctor to give me all the medical specifics. I was looking for someone who could talk me down with positive encouragement, offer true and good advice, and make sure I was doing everything possible to insure I had a plan moving forward.

I needed the support of a future friend I could always turn to at any time throughout my GIST journey. I quickly found out no such person existed. When I was approached by The Life Raft Group to volunteer in any capacity, I felt there was one way I could help "give back". What I did remember was the missing piece in the puzzle. The need for newly diagnosed people, like me, to have a mentor they could talk to and help and support them.

The volunteer LRG GIST Mentor program began in October 2019 and it has grown tremendously. Life Raft Group mentors have helped over 150 people, both patients and caregivers through their GIST journeys.

What does it mean to me to be a mentor? For me, it means helping someone who will need support and advice as they begin to navigate their journey. To make sure the mentee knows I am always there for them whenever they just need a friend to talk to or for guidance. To check on their well-being and to keep in touch.

Currently, we have 15 patient and three caregiver mentors. We are desperately in need of more. Unfortunately, there are new people being diagnosed weekly with GIST and wanting help, encouragement, support and advice. As mentors we also need help, support, encouragement, and advice. We take care of that by having a monthly virtual meeting where we just gather to "shoot the breeze", laugh, and talk about our lives and families. We are there to help each other with advice and support.

Please consider becoming a mentor. There is so much satisfaction to be gained by helping a fellow GISTer with their journey. Thank you and I hope to someday in the near future to welcome you into the mentor group!

<https://lifteraftgroup.org/lrg-gist-mentor/>



Our first group of GIST Mentors at a training session in 2019 at LRG Headquarters in NJ: Left to right: Rob Taylor, Julie Durkee, Carolyn DeWalt, Eric Lindberg, Santy DiSabatino, Kay Stolzer, and Marlene Nei

Ira & Kay Stolzer



Kay, who is originally from Texas, met Ira, a native New Jersey, in Kansas City in 1978, while visiting her former roommate. She was looking for a change

from Texas, and was thinking of relocating. Her roommate provided her with a fun apartment complex, and a large group of new friends. Ira had just begun his career with Hallmark Cards, and Kay began a new job in advertising. They dated for two years, and eventually married in 1980. They have been married for 41 years.

Neither could have predicted they would face one of life's biggest challenges - cancer. Nine years ago they heard those words, and while life has changed since her GIST diagnosis, it has become a piece of their lives, not the focus.

Kay's introduction to GIST was an incidental finding in a routine procedure. As fate would have it, her GI specialist had just completed a course about GIST. He reassured Kay and Ira that it was benign, but the tumor in her stomach could become malignant, and must be removed. Things moved quickly after that, and the surgeon they consulted with had a different point of view. Ira shared that the surgeon said he'd been out of the prediction business for a long time, and always leaves the diagnosis to the pathologist. After many preop tests, even the biopsy revealed benign spindle cells. The Chief of Gastroenterology, who performed the biopsy procedure, adamantly told them, "This is not cancer; I've seen cancer, and this is not cancer".

While recovering from surgery in the hospital, the surgeon informed them that the tumor was malignant, but they "got it all", and Kay was

cured. He told them Kay would simply take a pill for three years, and he had never heard of anyone who had problems with it. "The diagnosis was such a shock," Ira said. They were somewhat reassured by the surgeon's words, but Kay was frightened.

There were no GIST experts in Kansas City, and they didn't actually know they needed one. They even asked their surgeon to refer them to MD Anderson, to see a specialist, but he told them they didn't do that there, and they could treat her.

"The more I read, the more terrified I became," Kay said. "There wasn't anyone like me to talk to. I felt very alone in that. I had my hair and didn't look like a cancer patient. I was so distraught, the Oncologist I was assigned to, suggested I look at an organization called the Life Raft Group for support. It was there that I learned I did need to see a GIST specialist, and my life changed."

Kay and Ira had several heart-to-heart talks about her diagnosis, and what the future might bring for them. "He was an absolute rock. He never faltered," said Kay. When Kay asked him how he could be so positive, he reminded her that as a gymnast in college, he learned his mental toughness. He was the co-captain of the National Championship Team at Penn State in 1976, and his coach made them compete for their uniforms every week after each meet. This created a strong mental attitude, and the ability to compartmentalize. His feeling was, "If there is something to deal with, we'll deal with it. It could be potentially terrible, but right now, this is where we are." Ira elaborated on this explanation. "I have the easy part. She's the one actually going through all this." After nine years, they feel like they've figured out to handle things pretty well. They focus on what they can control, and what they know.

Kay, an LRG GIST Mentor, uses this technique for herself, and shares it with her mentees. "I have



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an imaginary box, and in it are all the bad things that could happen. I keep the lid on that box closed tightly, and store it on the highest shelf in my closet. If we need to bring the box down, and open it, we can do that together. In the meantime, it stays in the closet. You live your life the best you can." shared Kay.

The couple credit their compatibility for the enduring nature of their relationship. They always "liked" each other, as well as loved. "One of Ira's best qualities is that he makes me laugh every day," said Kay. Laughter can diffuse almost any stressful situation. Kay said that she often feels guilty about the way GIST has affected their



lives over the years. "But Ira just looks at me and says, in sickness and health, baby; in sickness and health. He's very kind, compassionate and giving. He's the best person I know."

Ira shared, "To me, Kay's always been my very best friend. We're close, and can always talk to each other. We can say anything. Talk about anything. Kay is amazingly supportive, super smart, wonderfully insightful and intuitive. The best thing about us is that we're so compatible. It's like we're hand in glove. We made a promise to each other when we first got married, that we would always fight fair, never call each other names or say anything we would be sorry for later. We would never have to say, I didn't mean that. We're both kind of wired the same way. It's just hard to take back words. And we've lived by that. We've never wavered from that."

Kay recommends the GIST Mentor program for the newly diagnosed, someone who might not have others to lean on, or just to have someone to talk to when you're going through a difficult phase of your journey. "The Mentorship program

is there to hold your hand. You are provided with a safe person with whom you can be vulnerable. When you meet someone dealing with cancer, you don't talk about the weather. You just dive right into the real stuff. You're not alone; there is always someone you can talk to that knows what they are going through and isn't going to judge them or tell them it's just a pill you're taking, or

I don't know what the big deal is, you don't look sick, or what's your prognosis?"

Likewise, Kay said that being a Mentor has enriched her life. "I care deeply for each of my mentees, and get to know them on a very personal level. It helps me connect with people and let them know that after nine years, I'm still here. I think that is reassuring. Every

conversation a Mentor has with a mentee is held in the strictest of confidence. The LRG has been immensely helpful and available in getting patients in to see a specialist if someone is facing roadblocks. "They just get right in there and help with connections. I believe I can be the bridge between the LRG and the mentee. If I can't help, I know the LRG will help get them where they need to be."

Ira had some good advice for caregivers, and balancing cancer and ordinary life. "I don't have any magical answers. To me, the best care you can give yourself is to stay the course. You may have setbacks along the way, and you need not get bogged down. This is a long journey, and it's best to stay calm, focused, and be supportive. I think that when you're a caregiver, you have to do things for yourself. I try to make plenty of time with my friends. I'm much more of a social person than Kay. I have to be with people, and I plan that. I like to play golf. Kay always encourages me to do those things. I'm very involved with Penn State. I serve on a few committees, and we've been season ticket

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holders for over forty years. That is my happy place. I love being there and seeing old friends. Kay is completely supportive of that, so when I'm able to have time for myself and the things I enjoy, it gives me more energy to be there for Kay. I think the worst thing for us would be to let cancer be all consuming. We work hard to have a normal life balance."

Kay is nine years NED, exon 11, and on Gleevec. She and Ira are the proud parents of two wonderful sons, daughters-in-law, and two grandsons, whom they miss terribly, and see as often as possible. They split their time between Kansas City and Florida. Still newlyweds at heart, every time they raise a glass, they quietly toast "lovers forever." Kay has been a GIST Mentor and a Board Member since 2019.

It's Time to Tell *Your* Story in 2022!
See our "It's Time to Tell the Stories" Campaign on page 10

Dr. Neeta Somaiah joins the LRG Medical Advisory Board

"I am really excited to join the MAB for the Life Raft Group. I truly believe that empowering patients with knowledge and resources greatly improves their cancer experience and outcomes. The LRG is one of the leaders in GIST patient support, and I look forward to making positive contributions with my other esteemed colleagues on the board."



Dr. Neeta Somaiah is an Associate Professor of Sarcoma Medical Oncology and serves as the Deputy Chair of Sarcoma Medical Oncology at The University of Texas MD Anderson Cancer Center in Houston, Texas.

She has thirteen years of sarcoma experience, and is board certified in Medical Oncology. Her primary clinical and research focus is soft tissue sarcomas, specifically liposarcomas and GIST. Dr. Somaiah currently serves as the Principal Investigator of multiple investigator-initiated trials and cooperative group and industry-sponsored clinical trials at MD Anderson, and has in-depth knowledge and experience in the design and execution of clinical trials.

Dr. Somaiah also has ongoing collaborations for translational research both retrospective and prospective, that contribute to the

understanding of these rare diseases, and explore the role of immunotherapy as a therapeutic avenue.

Sara Rothschild, Vice President of Program Services at the LRG, shared, *"It is a pleasure to have Dr. Neeta Somaiah join our Medical Advisory Board. Dr. Somaiah has many years of clinical and research experience in GIST. Combined with her medical experience, she demonstrates true compassion and dedication to her patients. Her unique perspective is an important asset to the Medical Advisory Board and we are thrilled that she is available to support the patient advocacy community."*

Welcome, Dr. Somaiah! We look forward to all that this collaboration will bring to the GIST community.



Rare Disease Day

February 28 - It's a day to raise awareness of the over 7,000 rare diseases that impact over 300 million people globally!

Show Your Stripes on social media with the hashtags #rarediseaseday #gastrointestinalstromaltumor #iamrare. You can read about more activities to join on RDD at <https://www.rarediseaseday.org/>

Conversations with the LRG:

A Conversation with the Rarest of the Rare

February 28nd 1:30 pm

A Rare Disease Day Presentation



Join our Director of Data Management & Research, Sahibjeet Kaur, as she chats with two GISTers who are 'the rarest of the rare'. These two patients share their stories of diagnosis, testing and access to treatment. This video debuts Feb. 28 at 1:30 pm ET:

<https://www.youtube.com/c/LiferaftgroupOrg>



Rare Disease Day Call for Stories - NORD invites you to share your story. Join the individuals and families who have contributed their personal accounts of living with rare diseases. Alone we are rare. Together we are strong! Read more here: bit.ly/ShareYourStoryRDD

Rare Disease Day at the NIH - Virtual Conference

Rare Disease Day at NIH seeks to bring together a broad audience including patients, patient advocates, caregivers, health care providers, researchers, trainees, students, industry representatives and government staff. The event is free and open to the public. Register & View Agenda here: <https://ncats.nih.gov/news/events/rdd>



Rare Disease Day at the FDA - FDA will host a virtual public meeting on March 4, 2022 to join the global observance of Rare Disease Day. The theme for FDA's Rare Disease Day is "Sharing Experiences in Rare Diseases Together."

Patients, patient advocates, researchers and medical product developers may benefit from attending this public meeting on rare disease product development. During presentations and panel discussions various

stakeholders will share their perspectives on and experiences in rare disease product development. Register & View Agenda here: <https://bit.ly/FDA-RDD>

Be A GIST Detective!

A New Informational Worksheet for GIST Patients - Talking to Your Doctor About Mutational Testing

As a part of our Biomarker Testing Campaign we created a new informational sheet to help patients talk to their doctors about getting mutational testing called "Be a GIST Detective."

Understanding the role of mutations and biomarker testing is one of most important things patients must learn. Uncovering the driving force behind each individual's tumors is not just important, it is critical. Biomarker testing is an opportunity to improve and optimize treatment – possibly avoiding unnecessary treatments and getting to the right treatment sooner.

In detective work, there are specific questions that will reveal evidence that allows you to see the whole picture. In this sheet we talk about the '5 Ws and 1 H' of biomarker/mutational testing to discuss with your doctor - the Who, What, When, Where, Why, and How of mutational testing for GIST patients. This information will help you advocate for the vital details you need for your best treatment.

You can find our 'Be a GIST Detective' sheet here:

<https://liferaygroup.org/are-you-newly-diagnosed/>

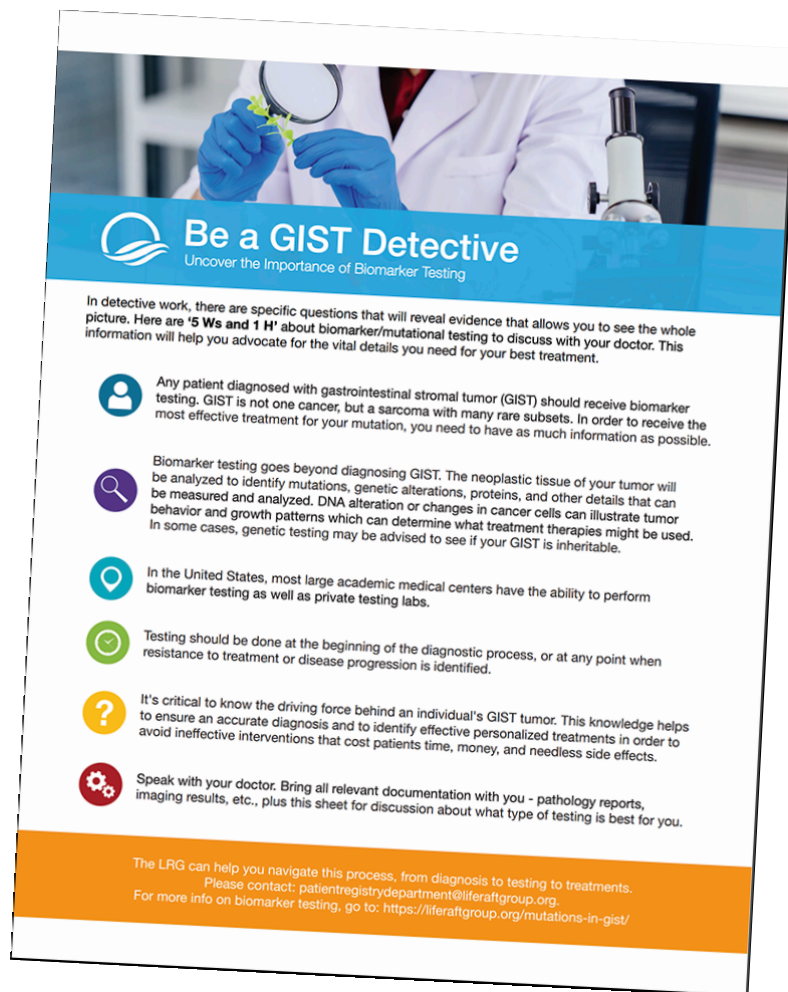
For more information and resources about mutational testing, visit these links:

<https://liferaygroup.org/timetotested>, <https://liferaygroup.org/2021/02/resources-list/>

To see information on our tissue testing initiative with Bayer, visit this link:

<https://liferaygroup.org/2021/10/tissue-testing-project/>

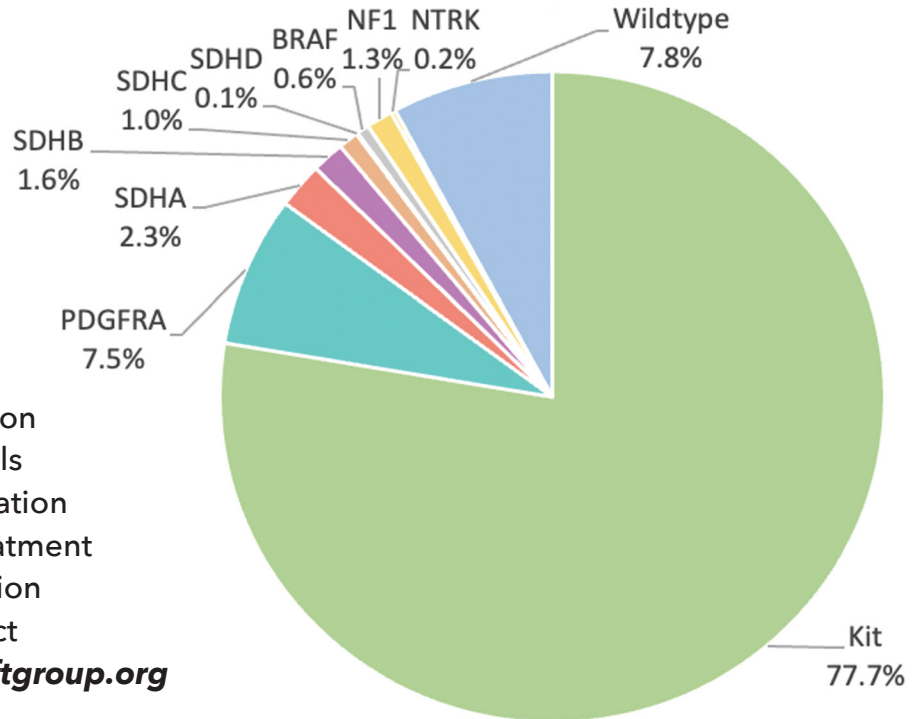
If you would like to talk to someone about obtaining mutational testing/tissue testing, please contact our Senior Director of Data Management & Research, Denisse Montoya, at dmontoya@liferaygroup.org





54%
of patients
(1325 people)
in our Patient
Registry
know their
mutation.

Distribution of mutations for patients in our patient registry that reported receiving mutational testing.



As a GIST patient, knowing your mutation can be one of the most important details about your disease. Knowing your mutation will help you get the most effective treatment for your mutation. If you need information about mutational testing, please contact Denisse Montoya at dmontoya@liferaftgroup.org



The Life Raft Group mourns the lost of our friend Anita Getler. She was a true friend, and a courageous survivor and GIST advocate. This photo of Anita from our Rare 13 campaign and shows her zest for life. She will be sorely missed.



The Life Raft Group is celebrating our 20th anniversary as a nonprofit in 2022. For twenty years, our organization has been serving as a life raft for others navigating their GIST journeys. The LRG, which began as a group of concerned patients and caregivers living with a rare and often misunderstood disease, continues our mission to help our members survive and thrive.

It is the perfect time for us to share the stories.

These stories are of those early pioneers who have helped save thousands of lives; the stories of our brave and inspiring members; the advocacy stories of the challenges patients face globally, and the story of this unique patient advocacy organization.

Throughout 2022, we will share stories, videos, and informative webinars to show the world who we are, what this strange sarcoma called GIST is, and what research is being done to find more effective treatments. We will remind GISTers that above all, they are not alone! This celebration will culminate with our biennial Life Fest gathering in New Orleans in July.

Help us celebrate this landmark anniversary!

- **Join our community** - It is free, and provides you access to many resources including our email support community, GIST Chat (<https://forum.gistchat.org/login>)
- **Join our Patient Registry** - Our Data Management & Research staff is available to help provide insights into your GIST.
- **Send us your stories** - We will be publishing them on our website (<https://liferaftgroup.org/member-stories/>) and in our newsletters (bit.ly/LRGNewsletters). Send stories to Mary Garland, Senior Director of Communications: mgarland@liferaftgroup.org
- **Attend our Life Fest 2022 celebration** - Gather with other GIST patients and caregivers as well as leading GIST specialists for an informative and fun weekend. (bit.ly/LifeFest2022)
- **Celebrate GIST Awareness Day with us on July 13** - Check out what it means to us and what we've done in past years (<https://liferaftgroup.org/about-gist-awareness-day/>) More info to come.
- **Volunteer your time** - Your gifts, talents, and donation of time are a priceless gift to our community. (<https://liferaftgroup.org/volunteer/>)
- **Become a GIST advocate** - Use your voice to raise awareness about GIST. (<https://liferaftgroup.org/advocacy/>)
- **Donate** - There are many ways to donate so that we can continue the level of services we have provided to our community for the past 20 years. (<https://liferaftgroup.org/donate-2/>)

"Stories have to be told
or they die, and when they die,
we can't remember who
we are or why we're here."

- Sue Monk Kidd, author

Side Effects Spotlight: Coping with Muscle Cramps

By LRG Staff

Muscle cramps are an involuntary muscle twitching that can occur during cancer treatment, and it is a common side effect that patients in our Patient Registry experience. GIST treatments including Gleevec, Sutent, Stivarga, Qinlock and Ayvakit can cause a reduction in levels of calcium and magnesium in the blood. It is believed that the reduction in these levels can be one of the causes of muscle cramps.



The Life Raft Group encourages patients to talk to their doctor about monitoring calcium and magnesium levels and to ask whether they should incorporate calcium and magnesium supplements into their treatment plan. In addition, a number of patients have reported low levels of Vitamin D while on medication. Vitamin D helps absorb calcium and it is a good idea to have Vitamin D levels checked.

Checking these levels can be done by a blood test. In some patients, low levels of phosphorus (hypophosphatemia) or high levels (hyperphosphatemia) have been reported. Monitoring phosphate levels may also be useful. Detailed more below, L-carnitine is another level that should be monitored if muscle cramping is an issue.

If you are unsure of your vitamin levels, a good starting point is to discuss doing a complete blood workup with your doctor to determine a baseline and to check for any deficiencies. The LRG encourages its members to always discuss these issues with their doctor before changing anything in their routine as taking too many of any supplement/vitamin can also cause adverse effects.

Here are some tips for easing muscle cramps:

- Increase your fluid intake. Dehydration can cause muscle pain, so make sure to drink a lot of fluids. We have had several patients report improvement in cramps after increased water consumption. This may be especially important if you are having other problems like diarrhea (which causes dehydration).
- Drink electrolyte replacement beverages (including Gatorade, Powerade and other electrolyte replenishing drinks) **Please note: Discuss these beverages with your doctor as some can have high levels of sugar.*
- Drink tonic water.
- Undergo a physical therapy program.
- Undergo an occupational therapy program.
- Make sure you are getting the appropriate amount of sleep.
- Try hot/cold therapy to relax the muscle(s).
- Make sure you are getting enough movement throughout the day to use your muscles.
- Try stretching.
- Reduce sodium/caffeine/alcohol intake as that can lead to dehydration.

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- Patients in the Life Raft Group Patient Registry share that Ivory Soap™ helps with cramping. Remove the wrapper and place the bar of soap between the bedsheets. Some patients say that this has significantly helped with their cramps, especially leg cramps. Some have also mentioned that when the cramps are severe, they will place a travel-sized bar in their socks to sleep.

Some patients on Gleevec can have an increased CPK (creatine phosphokinase) level in the blood. CPK is a marker of muscle damage and can be high in up to 57% of GIST patients taking Gleevec. It has been suggested considering testing CPK as part of the standard clinical chemistry workup of Gleevec patients as an objective measure of musculoskeletal complaints.¹

Besides these lifestyle change or adaptation suggestions, there are medications that can help to alleviate the muscle pain you experience (one possibility is muscle relaxants). Before starting any type of treatment, discuss your muscle pain with your doctor. Be sure to bring a record that details the onset, characterization, location, intensity, and duration of the pain along with any factors that have relieved the pain in the past. If cleared by your physician, you may take a non-steroidal, anti-inflammatory drug (NSAID) such as Aleve to alleviate the pain. Ibuprofen can be taken for a short period, if approved by your doctor; however, since there is potential for ibuprofen to affect GIST medication transport into the tumor cell, patients should probably not take it on a long-term basis. Tylenol can also be used if your doctor says it is okay, however, if you are taking Gleevec, limit Tylenol to 1300 mg per day (1/3 the normal maximum dose) as Gleevec slows the metabolism of Tylenol increasing the risk for liver damage.

It's also relevant to mention that if you are taking a generic version of Gleevec that you should keep an eye on the name of the manufacturer (found on your medication bottle, or ask your pharmacist) and note if your side effects are worse or better with a specific generic manufacturer. Patients in our Registry have noted experiencing different side effects on different versions of generic and they have also noted side effects becoming worse if their pharmacy changes the generic version to another manufacturer's product. If you notice a correlation, we recommend speaking with your doctor to see if there is any way you are able to change the generic.

Results of study on L-carnitine supplementation in patients taking imatinib²

In 2018, a group of researchers from the Asan Medical Center, Department of Oncology, in Seoul, South Korea began a study on the effects of L-carnitine on imatinib-related muscle cramps in GIST patients. In this study, 42 patients who had been on imatinib at least three years (300 and 400 mg daily) and were experiencing muscle cramps were enrolled and evaluated for the intensity, duration, and frequency of their muscle cramps. The effect of these cramps on their quality of life was also noted as these side effects can hinder adherence and interrupt or cause discontinuation of treatment. Trial researchers also gathered information on what these patients were currently doing to alleviate their symptoms.

Muscle cramps are thought to be caused by the impairment of energy metabolism which is considered a primary player muscle cramps in patients with chronic disease. L-carnitine is an ammonium compound which is synthesized by the kidneys and liver and acts as a transporter of long-chain fatty acids to the mitochondria for oxidation and the production of energy. Based on this, the idea was that L-carnitine deficiency could result in impaired muscle relaxation and be a possible cause of muscle cramps.

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Study participants were given 1000mg to 1500mg of L-carnitine (dependent on their dosage of imatinib). After three months, 83% of the participants showed significant improvement in the intensity, duration, and frequency of their muscle cramps as well as a substantial improvement in their quality-of-life measurements.²

This study has produced promising results for GIST patients with debilitating muscle cramps on imatinib though as always the LRG cautions beginning any supplementation without a doctor's approval. Though not all the patients in the study were L-carnitine deficient, it is best to consult with your GIST expert and have those levels checked before beginning any addition to your treatment.

Dr. Yoon-Koo Kang, one of the authors of the study, shared the details of their findings on in this video:

<https://liferaftgroup.org/2022/02/l-carnitine-muscle-cramps/>

Read abstract of the paper here: <https://bit.ly/L-carnitineMuscleCramps>

If you are not a member of The Life Raft Group GIST Patient Registry, we invite you to join. Your participation is so valuable since it helps us get a better understanding of GIST including side effects associated with the cancer and treatments. Our goal is to be able to assist patients just like you with information and beneficial shared experiences. If you have any questions, please do not hesitate to reach out to the Data Management & Research Department at patientregistrydepartment@liferaftgroup.org.



*Dr. Yoon-Koo Kang,
Asan Medical Center,
Seoul, Korea, co-author
of the study.*

As always, please consult your GIST expert before making any changes to your diet, nutrition, exercise routine, or lifestyle.
This information is not a substitute for their expertise.

References

1. Increase of creatine kinase value (CK) correlates with musculoskeletal complaints (MSC) in GIST patients during imatinib therapy, P. Allione, G. Grignani, S. Aliberti, D. Rota Scalabrini, F. Carnevale Schianca, A. Capaldi, R. Vormola, D. Caravelli, A. Galla, M. Aglietta, DOI: 10.1200/jco.2006.24.18_suppl.9509 Journal of Clinical Oncology 24, no. 18_suppl (June 20, 2006) 9509-9509.
2. https://www.youtube.com/watch?v=RPkp6m_bl68 (Presentation on Phase II Studies: Impact of L-carnitine on imatinib-related muscle cramps in patients with gastrointestinal stromal tumor)

You can read other articles about side effects here:

<https://liferaftgroup.org/2021/10/common-side-effects-how-to-manage-them/>

<https://liferaftgroup.org/managing-side-effects/>



An email community for GISTers
<https://forum.gistchat.org/>

Clinical Trials Update



By LRG Staff

In this summary, we continue highlighting recent clinical trials that are still recruiting in the U.S. which investigate potential treatments for GIST patients. Our GIST Trials Database lists over 70 trials that are GIST-related and ongoing around the world. Currently there are 12 GIST-related trials recruiting in the United States. In our last article, we listed several for different types of GIST mutations. You can read the previous clinical trials update (December 2021) here:

<https://liferaftgroup.org/2021/12/clinical-trials-update-december-2021/>

For further information about GIST trials including international trials, visit: The Life Raft Group Clinical Trials Website: <https://gisttrials.org/>. If you want to speak with someone about clinical trials, please contact liferaft@liferaftgroup.org.

For patients with advanced KIT/PDGFRa mutant GIST:

THE-630 Phase 1/2 - "A Study of THE-630 in Patients With Advanced Gastrointestinal Stromal Tumors (GIST)" (<https://gisttrials.org/iLRG/details.php?Trial=384>)

Site is at Dana-Farber Boston, MA Principal Investigator Suzanne George. Started January 3, 2022. The study will be conducted in two parts: a dose escalation phase, followed by an expansion phase. Plans to recruit 160 over a period of 42 months.

In the Phase 1 dose escalation phase oral THE-630 will be administered once daily in a continuous regimen. Primary objectives during the 28-day dose escalation phase are: 1. Number of patients with dose-limiting toxicities. 2. Determination of the recommended Phase 2 dose. 3. Determination of the maximum tolerable dose. 4. Safety analysis - number of participants with treatment emergent adverse events. For the subsequent expansion Phase 2 the primary objective is confirmed Objective Response Rate over a period of up to 24 months after first dose. In the escalation Phase 1 participants with metastatic or unresectable GIST will be admitted.

During the Expansion Phase 2 unresectable or metastatic GIST patients will be divided into 4 cohorts depending on prior TKI therapy. Cohort 4 will include patients who have progressed on or are intolerant to imatinib including patients in the adjuvant setting. The sponsor is Theseus Pharmaceuticals headquartered in Cambridge, MA. Theseus was founded in 2017 and emerged from stealth mode in 2021. On their web page Theseus describes THE-630 as "Our lead program, THE-630, is a pan-variant KIT inhibitor designed for patients with advanced gastrointestinal stromal tumors (GIST) whose cancer has developed resistance to earlier lines of kinase inhibitor therapy." Patients interested in this clinical trial can contact: Theseus Pharmaceuticals, 857-400-9491, ClinicalTrials@theseusrx.com. **NCT05160168**

About Phase 1 trials: It is important to recognize that Phase I studies are held to find the highest dose of the new treatment that can be given safely without causing severe side effects.

Continued on page 15

- The first few people in the study get a very low dose of the treatment and are watched very closely. If there are only minor side effects, the next few participants get a higher dose. This process continues until doctors find a dose that's most likely to be an effective treatment while having an acceptable level of side effects.
- Safety is the main concern. The research team monitors participants and watches for severe side effects. Due to the small numbers of people in Phase I studies, rare side effects may not be seen until later phases of the trial when more people are receiving the treatment.
- While some people may benefit from being on one, disease response is not the main purpose of a Phase I trial.

Phase I trials carry the most potential risk, but these studies do help some patients. For those with life-threatening illnesses, weighing the potential risks and benefits carefully is key. Sometimes people choose to join Phase I trials when all other treatment options have already been tried.

Spotlight on the LRG Data Management & Research Department

The Life Raft Group would like to introduce The Data Management & Research Department to our GIST community. The merge of data management and research brings stakeholders together to leverage shared resources and expertise toward identifying research needs for study development and prioritizing research requests from the GIST patient community.

One of the resources offered by our department is the LRG GIST Patient Registry. The goal of our Patient Registry is to collect health data from GIST patients all over the world to support future research, compare treatments & their side effects, and understand the natural history of GIST.

Direct access to patient interaction and scientific involvement provides us with an enhanced experience for the GIST community to share the analysis, interpretation of the data collection, and to promote collaboration among key stakeholders. Our frequent communication with patients and the scientific community enables us to voice all the key topics among both parties.

The data provided by patients is more than just an addition to a dataset, it is a key towards finding a cure. We are beyond grateful for the active participation of patients, caregivers, and all researchers/doctors that like us, are aiming to advance GIST research.

Programs offered by the Data Management & Research team include:

LRG GIST Patient Registry
Tissue Bank
Side Effects tracking
& management

GIST Specialists finder
Science Forums
Real World Evidence

Case Studies
Data Access
Data Collaborations



The LRG Data Management & Research Team

Left to right:
Senior Director,
Denisse Montoya,
Director, Sahibjeet Kaur,
Data Analyst Maeven Luedke
& Associate Antoinette
Pauwels

A Thank You from the Across the Nations

Lidia was searching for answers and when she reached out she found generous people willing to help assist her on the path to mutational testing and an effective treatment plan. She wanted to share those challenges and thank some of the people involved.



Lidia Kornienko

Hello, my dear friends and the Life Raft Group Team!

I would like to tell my story. I cannot keep silent because everyone who helped me deserves kind words and great fame. In January 2020, I found out about my disease, and I was not only in shock, but also terribly confused. I was overcome by questions: where to run, what to do? Really, are there no options and was this diagnosis a fatal verdict? Every day more and more questions arose, and the answers led me into a stupor and then new, more detailed questions appeared. Unfortunately, though I got answers, my treatment did not bring any results. I have a rare GIST mutation, which our doctors have not seen many times before. The doctors followed a general treatment protocol which I went through, but it did not bring a good result. I knocked on a lot of doors - many clinics and doctors, but there was still no favorable result.

I had to follow the path of a pioneer on my own and painfully studied the terminology, learned how to compose questions and how to find answers from various sources. I floated around the internet to get information about the diagnosis, treatment methods and specialists in a small circle of Ukraine and world practice. Thanks to the Afina Women Against Cancer Group recommendation and information from other people, I found The Life Raft Group, which started its activities in 2000.

When I joined the Life Raft Group, I discovered for myself two very good people: Sara Rothschild and Denisse Montoya. They did their best to help me, but it turned out that it was not that easy, because my tests and CT scans needed to be in English with correct medical terminology. They connected me with my *Angel Helper**, who despite her own full-time job, agreed to translate my medical documents from Ukrainian to English.

Continued on page 16

After work, she translated my tests result, CT descriptions, and other medical documents. She did it quickly and sent all these documents to the U.S. It was a great responsibility for this wonderful woman, who took everything under her control and at the same time supported me and did not let me give up for a single moment, because she herself also faced this problem.

My angel took on herself coordination of our activities, optimizing time and actions to achieve the desired result. She quickly and easily plunged into the problem; she acted quickly and efficiently and did not let me lose heart. She did not allow herself to relax and continued her search, finding answers to my questions, which gave me hope.

This woman helped me, a simple woman from a village, with breaking through and continuing treatment according to the protocols and clinical studies from America. She knows how important support is, how important it is for a person and their relatives not to be left in isolation, paving the way to recovery.

There also more people that appeared who cared about my life and situation. The Life Raft Group connected me with Professor of Pathology Raf Sciôt, from University Clinic Leuven, Belgium. My angel helper's colleagues assisted her to organize the transporting of my paraffin blocks and tissue slides to Belgium and then to the Leuven Clinic for testing. There was also Ukrainian doctor-radiologist, Vitaliy Kovtun, from the Poltava Cancer Center, and his daughter who agreed to provide English translation of my further treatment process to share with the medical community online.

Thank you for your help, it is so valuable. Without you I could not do it. Thank you for your supportive hands that held me, it is so valuable to me in this time. This is a huge support. I'm very glad that this aid arrived. I am doubly happy and proud that there are people in the world who are so responsive, soulful, and not indifferent. I will always remember your kindness. I sincerely thank you from all my heart for your timely and so necessary help, thank you for your assistance. Thank you so much for your hard work, professionalism, warmth, and cordiality. From all my heart, I wish you all big health, well-being in all spheres of life, a peaceful sky above your heads, and prosperity! No matter how strong we are, support make us yet stronger! It is like a breath of fresh air when difficulties pile up and suffocate you! Thanks for the support! I will always remember and bless you!

May the Lord protect you!

Sincerely,

Lidia Kornienko

**Angel Helper* - we have changed the helper's name to protect their privacy.*



Love, Actually

By Mary Garland, Senior Director, Communications



February brings its own unique challenges for us all. In parts of the world, we are dealing with cold weather, including snow and ice. Globally, we are still coping with the specter of the pandemic, navigating life with extreme caution.

Seemingly less treacherous, more benign is the holiday that falls on February 14th - Valentine's Day. Originally celebrated as a Christian holiday in honor of Saint Valentine, it is associated with a martyrdom story that has become embellished over the years. In the 14th and 15th centuries, it became entwined with the concept of "courtly love," but it wasn't until the 18th century in England that it became an occasion to send love letters, cards and flowers to express one's

affections. There are numerous legends and stories from around the world that have added to the day's mystique.

For many, the day brings expectations and additional pressure to make the day special. For individuals not in a romantic relationship, this can cause additional stress. For cancer patients who may be navigating their health journey alone, this may be a difficult day.

What if the holiday was "reframed" to truly be about love - not romantic love, but love for yourself and for others? Imagine a day when instead of expecting outward signs of affection from someone, that you spend the day showering yourself with love. Actual love.

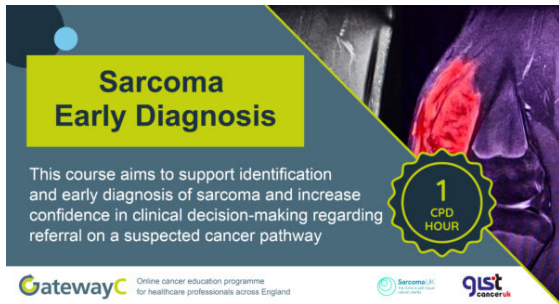
How to do it? Here are ten tips:

- Make a self-care plan for the coming year.
- Create a support system consisting of your medical team, family, friends or people in your disease support community.
- Plan to treat yourself each month to something that gives you joy. Simple, not necessarily expensive treats. Call an old friend. Walk on the beach or the woods. Listen to your favorite music.
- Make yourself a special dinner or order a nice dinner from your favorite delivery service. Set the table with the good china.
- Give yourself the gift of laughter. Watch a funny movie or sitcom.
- Spend a few minutes reading humorous Valentine's Day cards in the drugstore. Funny cards, only.
- Give the gift of your time to someone else. Reach out on GIST Chat, or volunteer to become a GIST Mentor. It will nurture you as well as others.
- Take care of your heart. Besides regular monitoring, investigate the elements of a "heart healthy" diet and lifestyle.
- Write a love letter to yourself. Put it aside to read whenever you are feeling low. List all of the things you like most about yourself.
- Remember that you are not alone. Whatever your circumstances, be assured that the Life Raft Group Community is here for you. You can join our support groups, engage in discussions on GIST Chat, or request your own GIST Mentor.



*And, if you choose to ignore the holiday altogether, know that is all right, too.
Just don't forget that loving yourself is true love, actually, every day of the year.*

GIST Notes: Around the World



GIST Cancer UK are delighted to have worked with online cancer education specialists GatewayC to develop a new course available to health professionals entitled 'Sarcoma -Early Diagnosis'.

bit.ly/SarcomaDiagnosisCourse

What it feels like: Living with GIST

Canadian GISTer Maureen went from feeling completely healthy to hearing a doctor tell her that she had gastrointestinal stromal tumours, a rare cancer that affects 1 in 100,000 people.

bit.ly/livingwGIST



A research team at the University of Cambridge is to lead a

groundbreaking study exploring genomics, in gastrointestinal stromal tumours (GISTs), with the aim of unlocking new treatment options for these sarcoma patients.

Co-funders Sarcoma UK and GIST Cancer UK will jointly commit £140,000 to the project, marking the first research collaboration between the two charities. Read more: bit.ly/GISTCancerUK

Open Access Perspective

Global Patient Involvement in Sarcoma Care—A Collaborative Initiative of the Connective Tissue Oncology Society (CTOS) & Sarcoma Patients EuroNet (SPAEN)

by [Bernd Kasper](#)^{1,*}, [Kathrin Schuster](#)², [Roger Wilson](#)², [Sorrel Bickley](#)³, [Jean-Yves Blay](#)⁴, [Denise Reinke](#)⁵, [Markus Wartenberg](#)² and [Rick Haas](#)⁶

New paper published by CTOS and SPAEN - Patients and patient advocates from Sarcoma Patients EuroNet (SPAEN), a global network of national Sarcoma Patient Advocacy Groups, and medical experts from the scientifically driven Connective Tissue Oncology Society (CTOS) came together on 9 November 2021 at an official ancillary event to the CTOS 2021 Annual Meeting. At the event, representatives of CTOS and SPAEN jointly discussed gaps and challenges in global sarcoma care and management. This resulting position paper highlights the main findings and possible future steps.

See the full paper here:

<https://www.mdpi.com/2072-6694/14/4/854>



NATIONAL CANCER INSTITUTE
Center for Cancer Research

The Pediatric and Wildtype GIST Clinic at the National Institutes of Health (NIH) is a collaborative effort between clinicians, research scientists and advocates, who share the goal of helping young patients with Gastrointestinal Stromal Tumor.

Pending the status of the global COVID-19 pandemic, we plan to hold a 2022 GIST Clinic September 14-16, 2022. Now accepting applications.

bit.ly/NIHGISTClinicApplication



GIST Specialist Dr. César Serrano received the Ramiro Carregal Emerging Talents in Oncology Research Award in Santiago, Chile. Read more at:

bit.ly/DrSerranoAward



By Dr. Matthew Lurin

Water of Life Ambassador

For the past few years, The Life Raft Group has held its annual "once in a lifetime" fundraiser, the Water of Life Fall event (WOLF) hosted by Dr. Matthew Lurin in NYC. Sadly, due to the COVID-19 Pandemic we made the hard decision to cancel the 2020 event.

However, in a happy turn of events this year, whisky aficionados gathered for the 4th Annual WOLF to enjoy rare whisky and raise funds for GIST research. This year's WOLF was once again held at our original home Keen's Steakhouse on November 10th, 2021.

As one of the first live events held (since the pandemic began) we were both excited and nervous. Would people want to come? Would brands participate? Do people have a desire for rare whiskies in this new climate? We experienced a wonderful sold-out virtual event this past July, but how would the reception for in-person turn out?

Our reliable brands were quick to respond and were prepared to shine as always. What would the WOLF be without our finishing Octomore pour? Without the launch of the next Paul John Christmas? Without new and rare releases from Westland and Glen Moray? We didn't need to worry, they were among the first to sign up!

Even original WOLF ambassador Raj Sabharwahl, who expressed regrets he would be on vacation, had to be a part of the event and donated a new and rare Waterford. Old favorites like renowned independent bottler Signatory were there, and this year they were joined by another famous bottler, Gordon & Macphail, who not only brought a ghosted distillery bottle, but our oldest pour yet, the 45-year-old Benromach.



Louise McGuane, the founder of JJ Corry herself joined us when her ambassador was unable to fly in, and has now claimed the WOLF as has her own event to attend in the future. There were single casks from Glendronach, and Glen Grant, an official Keeper's Cask from Pat McCarthy, special bottles from Ethan Kelly who represented Acker Wines Auctions, limited releases from David Schmier, who attended with Mike Miller from the renowned Delilah's in Chicago (with their own Compass Box Bottle in hand).

We were joined by newcomers to the WOLF from Aberfeldy, Aberlour, Arran, Dewars, and old friend Simon Brooking from Laphroaig was there making his WOLF debut as well. Compass Box, who was the donor of the first bottle we opened at our first WOLF, was able to bring their new No Name 3, which helped launch cigar hour.

But what about guests? As you can imagine a list like the one above is a whisky lover's dream, and when you pair that with some mutton from Keen's, and the appropriately named Wagyu Cigar from Alec Bradley, it's no surprise the tickets sold out quickly.

Sadly, over the years we have lost some of our original guests to GIST and other cancers, and this year we paid respects with a bottle donated by one of our original "Water of Lifers" Peter Silver, who before he passed earmarked a bottle of Springbank 21-year-old that was released in the 1990s, and is appreciated as one of the

Continued on page 21

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finest Springbanks ever. Our toast to lost friends was a somber moment, but reminded us of the importance of having events like this.

Every year the Water of Life Charity Event raises important funds for the Life Raft Group in the fight against GIST. The event itself is considered one of the best whisky events in the world by many aficionados due both to the amazing selection of whiskies and the people in attendance, both those who enjoy the amazing drams and the experts that donate them and educate us about them.

Equally important is to remember that this is a charity event at its core, and that guests not only find this evening a great way to celebrate life, but to help others improve their lives through the work of The Life Raft Group.

So, this year, perhaps you will join us at one of our live or virtual events, and "Drink Whisky to Fight Cancer" for an unforgettable night! (or 2 or 3 or...)

Slàinte mhath!

These funds enable the LRG to continue our mission to enhance the survival and quality of life for patients and caregivers living with GIST.

To our wonderful GIST Community,

We would like to take a moment to thank you for your generous gifts of time, talent and treasure over the past year.

Walking side-by-side with all of you during the continued challenge of the pandemic has been an honor. Your continued support, whether through your generous donations, volunteer projects, attendance at our virtual events or through sharing your data for research have enabled us to help many achieve positive outcomes in their GIST journey.

Your support for one another through our Mentor program, online support groups and GIST Chat continues to inspire us. You have helped us to expand our reach across continents and have supported advocacy efforts globally.

We continue to be both grateful, and amazed but what this rare disease community can do!

With heartfelt thanks to all of you,

- The LRG Board of Directors and Staff

Interested in Volunteering?

Contact: Diana Nieves, Senior
Director, Outreach & Engagement
dnieves@lifteraftgroup.org

See our calendar for support groups, GDOLs, and other events: <https://lifteraftgroup.org/event/>
Contact dnieves@lifteraftgroup.org to sign up for support groups/

What's Happening?

2

0

2

2



GDOL Tennessee - Virtual

February 25 - 2pm to 4pm CT/ 3pm to 5pm ET

<https://lifteraftgroup.org/event/gdol-tennessee-virtual/>

Make a Note!

GDOL North Carolina - March 24th

GDOL DC - April 27th

In person GDOLs:

GDOL Miami, May 14th

GDOL San Diego, Sept. 24th



Walk with Us for #GISTResearch!

Join family, friends & LRG staff on April 9th, 2022, at 8am in Verona Park, Verona, NJ

NJ GIST Do It Walk

Register:

bit.ly/GISTDoItWalkNJ2022

Sponsor this event! Contact:

jnowak@lifteraftgroup.org

LIFE FEST NEW ORLEANS 2022

Friday, July 29th - Sunday, July 31st

Register & Book your hotel today!

Gather with other patients & caregivers and experts in GIST care for our biennial meeting to experience expert medical knowledge, patient stories and to celebrate 20 years of the LRG.

bit.ly/LifeFest2022



Thank you to our Major Donors for December & January!

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	Joy and Doug Knopp		

Two Simple, but Impactful Ways to Support the LRG

1



thanks
for your
support

A. It's convenient for you.

Your donation of \$10 a month or more can be automatically paid each month. No fuss or remembering to send it in.

B. It's a consistent source of funding for us.

Even a donation of \$10 a month helps us continue to produce webinars, GDOLs, educational materials, and contribute to #GISTresearch.

Want to become a GEM?

<https://lifteraftgroup.org/donate-2/>

2

Remember to use
amazonsmile

and designate the
Life Raft Group
as your charity.

A. Set it and forget it.

Pennies add up quickly! Go to smile.amazon.com for desktop setup. On your phone, go the Amazon mobile app and select Amazon Smile in Settings and select

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