

Ensuring no one has to face GIST alone

In Loving Memory: Mary Pasiewicz, Bhakti Banning, Manuel Frangitelli, Douglas Morgan, Jeff Bernstein, Arun Krishnan, Karin O'Neill, Charlotte Lechten, Gayook Wong, LeAnn Daniels, Wondia Staples

Thriving & Challenging Yourself While Living with GIST

Two GISTers Share How They Are Reaching Their Goals

- Carolyn Tordella, Assistant Director, Communications

GIST patients face many obstacles and challenges to get to a place where they'd say they were thriving. Physical challenges from surgeries, pain, and side effects can severely change the lifestyle and activities they enjoyed before GIST. Two GISTers, Elsy and Stijn, one from the U.S. and one from Belgium, had to face those changes and both decided they wouldn't accept an altered version of life and strove for something more.

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Common Side Effects & How to Manage Them

- Pete Knox, Senior Director, Research

Every GIST patient (and person in general) is unique, however, there are some common issues that patients may face during their GIST journey. The LRG GIST Patient Registry has collected data on patients' diagnoses, treatments, evaluations, and other factors for close to 20 years. Some treatment records go back even further and from them we have been able to note some common patterns that make up what we call a "patient journey."

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Hitting the Target

Many years ago, I was tested during basic training to determine whether I could accurately fire a rifle. The test was based upon being able to hit a target from a set distance. Somehow, I did it and was given a marksman badge.

Imagine instead if I had hit the wrong target on the firing range. No badge would be awarded and I would receive the incredible wrath of an outraged sergeant telling me what he was planning to do to me.

Fast forward and I am now in charge of the Life Raft Group, a global organization striving to keep patients alive with a rare cancer called GIST (gastrointestinal stromal tumor). The really good news is that we have identified a number of different treatment targets at which to aim a number of new drugs.

Imagine instead that a doctor prescribes one of our wonderful new drugs for the wrong target because they did not order an available diagnostic test to identify what the right target was. The patient takes the wrong drug and suffers from its side effects as the cancer continues to progress. During this time the patient and the insurance company pay for a drug that cannot work and the patient's family pays with lost days of life.

It happens all the time. In fact, only about 26% of U.S. GIST patients* receive an appropriate diagnostic test that would have ruled out drugs that do not work and ruled in some that could. How could that happen?

The problem is the lethal time gap between the discovery of highly effective targeted diagnostic tests and treatments and their implementation into the best practices of the general physician.

The solution is that rare cancers should be treated only by physicians who are experienced in GIST management. That is why the Life Raft Group constantly identifies who these GIST Specialists are and advises GIST patients to seek them out, at least for a consult, to determine the best targeted treatment.

To die from a cancer for which there is no available targeted treatment is a tragedy. To die from a cancer for which there is an available targeted treatment but to be given the wrong drug for that target is totally unacceptable.

“The problem is the lethal time gap between the discovery of highly effective targeted diagnostic tests and treatments and their implementation into the best practices of the general physician.”

- Norman J. Scherzer

**That number is 55% among LRG GIST Patient Registry members.*

The LRG recently published "*The Importance of Biomarker Testing for Effective Treatment of GIST Patients*" in LRG Science, authored by Sahibjeet Kaur, our Patient Registry Supervisor. These case studies illustrate the importance of testing early in a GIST patient's journey.

The Importance of Biomarker Testing for Effective Treatment of GIST Patients can be found here:

<https://indd.adobe.com/view/a7905756-4e67-4518-84d0-e8f7f7c43d7b>

It's Time!

The LRG launched a year-long campaign called *It's Time*. It is time to stop talking and take action to assure patients get tested. The goals of this campaign are to improve the understanding of biomarker testing in the cancer community and increase the number of patients tested.

View our *It's Time* resource list: <https://liferaftgroup.org/2021/02/resources-list/>



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. Our **Biomarker Testing Campaign, It's Time**, has a goal to get all GIST patients to be aware of this important tool for their treatment path and get tested.

For more information on mutational testing, visit these links:

<https://liferaftgroup.org/timetogettested> and <https://liferaftgroup.org/2021/02/resources-list/>

If you would like to talk to someone about obtaining mutational testing, please contact our LRG GIST Patient Registry Director, Denisse Montoya, at dmontoya@liferaftgroup.org

Discover the different ways that you can help fund GIST research. Become a GEM (Give Every Month donor), become a Major Donor, sponsor an event, or start a legacy fund. Whatever you choose to do will help accelerate critical research that brings patients more clinical trials, new treatment lines, and one step closer to a cure.



donate

Help us provide services to GIST patients & fund GIST research.

Donate today!

liferaftgroup.org/donate

Need more info? Contact: DNieves@liferaftgroup.org



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Elsye Walker, Triple Crown Hiker



Elsye was living in Tahoe, Nevada in December of 2020, working as a lift operator at a popular ski resort. Skiing was a passion for this Flint native as well as a love of nature. She had spent the last six years working seasonal gigs

that kept her outdoors and gave her the freedom to work six months and hike for the other six.

"I don't think I was cut out to be 'normal'. I tried the traditional route: went to college, got my master's degree in Community Planning, got married, got a house and then realized that this was not the kind of life that I wanted. I wanted to do and see other things and especially travel and that's what I've been doing for the last twenty years. And I learned, during that 20 years, that I'm stronger than I thought," Elsy said about her lifestyle.

That December, Elsy had been making plans to take avalanche training and do some backcountry skiing, but she started to feel unwell. This feeling lasted about two weeks. She'd just returned to Tahoe from a trip to Joshua Tree and was feeling wretchedly tired. She thought it could possibly be Covid so she went to the hospital to be tested and passed out in the parking lot. It turned out that Elsy was severely anemic and had lost enough blood to warrant a transfusion.

"And that's when all the tests started, and they found out about the tumor. It was lucky that I went to the hospital for that Covid test instead of just an urgent care," she shared.

Once the doctors told her that she needed surgery right away, (January 2021) Elsy traveled home to Michigan. "My family insisted that I come home. My family has a history of cancer so they wanted me to go to a center they trusted. They removed the tumor (clear margins) and did a partial gastrectomy.

The doctors at the Karmanos Cancer Institute in Detroit are very familiar with GIST. They took really great care of me."

Elsye was in the hospital for a month after her surgery because she was also dealing with fluid in her lungs which required a stent. A month later, in April, she began a regimen of Gleevec, heart medications, and acid reflux drugs. Her personal plan was to return to life as normally as she could as soon as she could. For most of us that would be a big challenge.

Elsye was encouraged at a young age to do whatever she set her mind to by her parents and she took this mindset into her GIST journey. "Even though I grew up in Flint, as a child, my parents always said to us kids, 'whatever you want to do, you can do it,' and that's how I have always lived. I biked across Iowa 11 years in a row, I've done Burning Man, and I've been skiing since 4th grade. I like to get out and try new things, do exciting things, adventurous things."

Elsye accomplished the Triple Crown of Hiking (before her GIST diagnosis) which means that she has hiked the Appalachian Trail (2,193 miles in 2016 & 2018), the Pacific Crest Trail (2,654 miles, 2015), and the Continental Divide Trail (3,100 miles, 2017). She is the first Black woman to complete all three trails.

She commented that the Continental Divide Trail was her favorite because of the sights, challenges, and people she encountered along the way.

After her surgery she wanted desperately for her life to go back to "normal" as if nothing had changed. Training, however, for multi-week hikes is intense.

Elsye said, "When I'm training for a long hike, I build up to 20-mile days."

"On those long hikes you have nothing but time to think. All those things in your regular life that you push to the back of your mind. Those things all of a sudden are front and center and you ruminate over them, over and over, until you figure it out. You can't escape yourself out there. It's also very meditative to hike like that every day. To feel like you don't have all that



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noise in your head. It's also a very creative space for me. I wrote a poem out there once. It really clears your head," Elsy said of the solitude on the trail.

As she recovered and learned about her body post-surgery/new treatment, she said that she "planned to take the summer to do a lot of short hikes and build up my strength in order to hike the Arizona Trail in the fall which is 800 miles.

"Hopefully I can get my body ready for that. I need to do it mostly to reassure myself that I'm back and that everything's ok."

She continued, "I've had tons of tricky situations. Animals, running into bears, being awakened by a grizzly bear, other sketchy hiking situations. When I hiked the Pacific Crest Trail, my first trail, about a thousand miles in, I fractured my ankle. At the time I thought it was a sprain so I just kept hiking and pushing through that. The doctors I finally saw couldn't believe it. And I continued to finish the other two trails and I still haven't had that ankle fixed...I have a lot of women who connect with me about hiking and they're afraid and I think as women we have that put into us as young girls. We're not as strong or we're fragile. And it just kind of lives inside of you. And if women start being stronger and believing that they're stronger, we will be stronger. You will be stronger. You can be afraid but keep moving forward."

"Training for the Arizona trail made me realize it wasn't

about the trail at all, it was about facing my own fears. Fear that I wasn't that strong woman, that I was not the same. But I'm not the same. Cancer treatment not only affected my physical health, it affected the way I feel, think, and even the things I like to do. Just like a long hike I am stronger for going through it."

Moving forward, Elsy has returned to hiking, exploring what she can and can't do. The days after surgery were filled with 'can't' do, muscle pains, and digestive issues, "Learning to live with a cancer diagnosis has been difficult and very stressful. But you guessed that. The change in my cognitive/physical abilities has caused significant distress. I become overwhelmed, at times, with multiple tasks, distractions. Just leaving the house for a social occasion leads to stress. I'm used to hiding that though. The muscle soreness and hip pain really blows as you may have heard I like to walk. My long walk plans will now be different than before and that's ok," Elsy wrote in her blog, *Wandering Chardonnay - Life Explorer*.

Elsy also wrote this entry before her first long hike this past August, a multi-day trail, the Trans Catalina Trail (38.5 miles) - "Waking up in my tent I felt the familiar pit in my stomach like before every backcountry hiking trip. But this was kinda different. I can't do this. I'm not sure I want to do this, what if something goes wrong, breaks, hurts...When did I become this person. Oh, yeah it came with my cancer diagnosis. Side effects: Fear and self-doubt."

Elsy commented on this recently: "The thing about long distance hiking is you realize not only your plans will change, but so will your path. Embrace the change and keep moving forward. Hiking the Arizona Trail is not in the cards for me this fall. But short hikes from Joshua Tree National Park to the La Jolla coast are; different is good. Now to tune up those skis because the mountains are still calling."

Read more about Elsy's adventures & dealing with GIST on her blog at <https://wanderingchardonnay.com/> and [elsyw](#) on Instagram.



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Stijn Belmans, Ultra Marathon Runner

Stijn's story is somewhat similar to Elsy's except for the fact that he has been a GISTer for much longer. He thought of himself as fairly active pre-GIST, playing volleyball and running short races (10Ks) but after his GIST diagnosis, surgery, and commencement of treatment, he found that fatigue became a constant and debilitating side effect.

This GIST journey began in 2016. Life was going well – he was working in Human Resources for a non-profit organization dealing with youth, he was active, and he had no complaints health-wise, except for occasional stomach aches which he chalked up to stress. Just as Stijn was transitioning from one job to a new one working with at-risk youth late that summer, he found himself suddenly in a lot of pain. At a regional hospital near home, doctors found the source of the pain, internal bleeding from an unknown source. That source later became an abnormal lump of cells. At that point he was told it would most likely not be harmful. He was sent to the University Hospital in Antwerp for the surgery in October. At that point all Stijn knew was that he had a very rare anomaly and he just wanted this 'mysterious' thing removed.

The plan was to perform the surgery laparoscopically but that proved too difficult due to excessive bleeding and the amount of metastasis. Twelve days after the surgery the doctors came up with the diagnosis of GIST, which turned out to be exon 18 WT and his oncologist started him on Sutent in December of 2016.

"I didn't research deep into GIST at first, I trusted my doctor's opinion and I got a second opinion as well (a GIST specialist, Dr. Patrick Schöffski, UZ Leuven). He spoke to me for a long time on a very busy day in the clinic. I knew it was something rare, and the wildtype designation was even rarer. He gave me some numbers and said that the medication will make you sick but you'll get used to it or we'll have to change it up. Side effects were hell at

first. Many side effects. Hands, feet, stomach, mouth," he said Stijn.

Emotionally, Stijn said he really only had one very dark day. "Dealing with it was hard, it was a harsh blow, but I landed on my feet, surrounded by good people. I had learned from other issues in life that you have to look for the 'gain' so I tried to look for the profits in this situation. I looked for positive things – I wasn't going to have to do chemo or radiation therapy. I wasn't dying immediately. I thought, ok, the profits are that life is fragile and that it could end at any time so I started living my life really vigorously."

After healing from his surgery, Stijn went back to volleyball and his regular schedule of activities, but said that this was not a complete success. "After my first match I remember laying for 15 minutes on my back on the floor completely empty. And even during the game, someone called out sick so I played the whole game feeling pretty empty. Fatigue was a big issue. I had to sleep after work. But I still stayed very active. I kept working with young children. People thought everything was going really well but it wasn't that way. I only ate spaghetti for about six months because I could handle that a bit. It took everything out of myself to keep going which was not good."

He had scans every three months but talked with his oncologist every six weeks to discuss how he was doing on the medication. Due to the extreme fatigue, they tried lowering the dosage of medication, but fatigue was still an issue and rest wasn't helping.

"I happened to see a lot of information on cancer patients and survivors writing about sports and being active as a way to counteract the fatigue caused by medicine. And I started to create goals for myself. I had made a bucket list which I completed pretty fast because I was so conservative. I was not being very hopeful so I chose things that wouldn't take



me a long time. I was thinking pretty short-term. Now I'm planning a bit more forward and I began doing lots and lots of things - travels, challenges."

One of those activities include a race called Spartacus held in Belgium which was a combination of obstacles and running. Stijn said that it seemed to him to be something impossible to do, even before he got sick.

Similar to Elsy's mindset, Stijn needed to prove that he could persevere mentally and physically as he once had.

"I winged the training regimen on this one. I just needed to prove that I could do it. And I did it. I was completely drained and couldn't walk for three days afterward. Probably not the way to go but I proved to myself that I was capable of doing something that a lot of other people weren't capable of doing. Back then I wasn't training properly so I didn't see any increase in energy but it broke down some mental barriers for me. I am capable of doing physical challenges and I can rise above myself and I am not broken" Stijn continued, "And then afterwards, I did some smaller runs and I did races on really bad days (as there are good days and bad days) I suffered a lot running on those bad days, but I always finish. One race I was running was with friends ten years younger and healthy and they were pulling me along. It was really hard. And then I had the idea that I wanted to run hills and do trail running just to challenge myself."

Stijn wanted to keep challenging himself, and the fatigue was still an issue, so he decided to do longer runs.

"I wanted to do this longer (25 km) race in Ardennes (an area in Belgium with vast forests of broadleaf and fir, hills, and fast-flowing rivers) which is really hilly and I talked to my oncologist. The doctor said it might not be the best idea but I'll send you to the sports department of the hospital. So, I went to the sports department of the university hospital and they tested my heart, my body. I did the running test on a treadmill (stress test), blood tests, and such. They

told me I was in really bad condition; your shape is not good. In order to do the race, I wanted to do, they said 'You have to train properly, based on heart rate, as if you're going to be running a marathon on the date that you're doing that race.' And this was the start of a really good thing because I started training by , throwing away everything I knew before. And from that moment on I began to beat the fatigue. I started running by and it meant the first two or three months I had to walk a lot more than I ran -because my was too high when I was running, I had to stop and walk, slow down and then run again. It was frustrating. Sutent makes my faster, so this was frustrating at first."

He needed to build up his endurance and to employ the concept of 'flow.'

"I'm really into the philosophy of 'flow'. If you are competent or able to do things that you challenge yourself to see just how competent and capable you are. And if the challenge is big enough and you're up to the task, you enter a state of flow and you really move forward."

Stijn continued to challenge himself, battling the fatigue successfully and building up his endurance.



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Stijn entered the Icelandic Laugavegur Ultra Marathon Race 55K. He had hiked this trail in the past in four days sleeping 12 hours in between the day hikes, so he knew the terrain.

He said this about the race: "I wasn't capable of doing that at the moment I decided, and I had to build up to that. I had to stay in the state of flow - I'm going to go there and challenge my level of competence. I had a trainer who challenged me and I became more fit and skilled. If I'd kept running the same distances, I'd get bored. The state of flow and continually challenging myself is a good mindset."

Stijn completed the race in 7 hours and 40 minutes. He worried that he would need the maximum amount of time which is nine hours, but he trained so well and did better than he anticipated. The only stops were for toilets along the way. He consumed an energy gel pack every half hour and concentrated on carbs and sugar for energy, avoiding fiber since that fills you up. He had some issues along the way and wasn't feeling 100% but he endured.

"Before I didn't have to think about anything, I just did it. Now I had to start considering the 'details' more and I have gained so much and gone further in my physical fitness than I ever thought I could. I used to think that marathon runners were so stupid - I didn't understand why you would want to run that long and far. The biggest race I had done was a 10 mile in Antwerp and that felt like a bit too far but I did it. And in dealing with GIST, I had this mindset change and wanted a bigger challenge for myself to encourage others and inspire others."

Follow Stijn's journey on Facebook:

<https://www.facebook.com/groups/1856335481355229>

Every GISTer has challenges due to surgeries, and medications and their side effects. No one is suggesting that every patient become a super athlete. These stories are meant to inspire you to work towards the best life you can live as you thrive with GIST whatever that looks like. If you are having issues with fatigue, please consult your oncologist for ways to overcome this. In our experience in talking with patients and physicians, treatments, anemia, low B12, and lack of activity can contribute to fatigue. Please consult with your physician before making any changes in your medicines, supplements, or exercise routine. You are also welcome to join the LRG community and our GIST Chat forum where GISTers privately discuss their GIST journeys and how they work to thrive.



Again, while no journey is identical, we can learn from commonalities and use that knowledge to help patients thrive with GIST. Leveraging this registry knowledge, we recently began collecting more systematic and detailed information

about patient side effects in an attempt to not only better understand what these side effects are, but also how to help patients cope. We also started collecting “interventions”, or the methods which patients use to treat their side effects. In addition to the interventions, we also asked patients to rate the success of these approaches, so as to build up a library of possible strategies we can share with patients to help them treat their side effects just as successfully.

Treatment of side effects is important for a number of reasons. One perhaps obvious reason is the impact on quality of life. This is true even for patients who aren't on any medication, as it is possible that some side effects may come from the disease itself (or other conditions besides GIST the patient may be going through). Another important reason, that may not seem as obvious at first, is unique to patients who are on medication as their side effects may impact their ability to actually take their medication as prescribed. This is referred to in the scientific literature as compliance or adherence. As you might imagine, if a side effect affects your ability to take your medication, this may mean the medication won't work as effectively, and that can lead to negative outcomes like medication resistance or tumor progression. Thus, for those who do experience side effects, especially ones that have a major impact on quality of life and/or adherence, management of side effects is an important part of any patient's treatment journey.

This article will focus on a number of side effects reported by GIST patients. They have been included for two main reasons; some simply because they are reported with higher frequency, and others, because they are interesting from a data perspective, since their frequency seems to vary based on a number of factors, such as the patient's age or gender.

One other issue that has been observed is that many of the side effects common to GIST are also common to a number of cancers (and other diseases as well), which means that there is a large amount of content already published for patients. One excellent source is our own website where the side effect management page (<https://liferaftgroup.org/managing-side-effects/>) lists a number of the side effects detailed in this article, and also lists specific side effects for both Gleevec and Sutent.



FATIGUE

Fatigue is by far the most commonly reported side effect by LRG Patient Registry members. It is also one of those side effects that is commonly reported by patients facing other cancers or chronic diseases. While everyone, including people not dealing with cancer or another chronic disease diagnosis, may face fatigue from time to time, what we are most concerned with here is fatigue that occurs more consistently and has a demonstrated effect on quality of life. This latter supposition (that most people experience fatigue) is what, from a research perspective, makes it so hard to find causative factors. How do we know if the fatigue is caused by the disease, the medication, increasing age, lifestyle factors, or a combination of all of these? In any case, what we can conclude is that treating the side effect is of the utmost importance.

One possible complication of GIST medications, like Gleevec, is that they can lead to anemia, which is the lowering of a patient's red blood cell count. As red blood cells carry oxygen, a reduction can contribute to fatigue. If anemia is suspected, you can talk to your doctor about possible medications like Procrit that can increase your red blood cell count, which may help reduce your fatigue.

Even for those patients not taking medication, fatigue may still occur due to the nature of the disease itself. This can be due to bleeding tumors or low iron count.

In the latter case, iron supplementation might be helpful. In addition to these methods to treat fatigue, strategies used by patients with other diseases (or no disease at all) might be



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helpful. Many of these are fairly common-sense recommendations – pacing yourself so as not to get too tired, taking naps when possible, and even joining a support group to learn about (and share) strategies with others. Some may find that light exercise actually helps reduce fatigue as well.



DIARRHEA

Diarrhea, much like fatigue, is a very common side effect. In addition to the quality-of-life impact it may cause, including limiting ability to work or travel, a compounded issue involves nutrition. Patients may have difficulty absorbing enough nutrients if the diarrhea goes on for long periods. Coping with this may require a bit of an individualized strategy, as the foods one patient may be able to tolerate may be profoundly different than those of another. Experimenting with what works for you and adjusting accordingly gives you the greatest chance of success.

In general, however, there are a few overarching strategies that may help to start: try to eat smaller meals more frequently rather than large ones; drink plenty of water and/or clear liquids, broths, etc.; avoid higher fiber foods at least at first as they may help with bulking of the stool; and try to concentrate on higher nutrient foods (i.e., protein, minerals, and calories) whenever possible. Spicy foods may irritate the digestive tract, but again that can vary by the individual. In general, stick to a small number of foods that you can tolerate, and then add new foods in individually over time to see if they work for you. There are also of course medications (often over-the-counter) you can use – just remember to discuss these with your physician and/or pharmacist first.

One thing to note about our observations in general is that patients often report that their side effects reduce in severity over time.



NAUSEA

Another very common side effect for patients across many diseases, nausea can best be characterized as “feeling as if you are going to vomit” (as opposed to actual vomiting). Sometimes these issues go together, and sometimes a patient experiences nausea but not vomiting. Vomiting is a more severe issue as it directly affects nutrition, and may also affect whether or not you are absorbing the medication you are taking. Nausea can still have quite an impact if it causes the patient to eat less, or stop taking their medication. In addition, nausea may sometimes be accompanied by lightheadedness or dizziness, which may increase the risk of falls. Perhaps the best way to treat nausea is to try to prevent it in the first place if possible. This can be done with medications, often referred to as antiemetics; some are available over the counter and there are also stronger ones available by prescription. If you do take an over-the-counter version, it is extremely important to consult your doctor as the drug may have side effects of its own.



SKIN ISSUES, RASHES, HAND & FOOT SYNDROME

Skin issues are a common side effect of many medications, and they often can be placed on a scale of mild to severe, with minor skin eruptions and rashes on one end, and more pronounced issues like hand and foot syndrome on the other. In all of these cases, we are referring to irritations of the skin that can, if not treated, lead to blistering, and possible infection. This can lead to a number of quality-of-life implications, up to and including decreased mobility if the irritation is on the feet as is often the case with hand and foot syndrome, or even difficulty taking medication if it is on the palms. If a patient has a condition such as diabetes, or another that affects wound healing and increased susceptibility to infection, these issues become even more of a concern and should be dealt with as soon as possible and brought to the attention of your doctor.

If it appears as if the skin issue has been brought about by medication (such as when first starting a medication, or increasing dosage), it is important to

let your doctor know as they may be able to adjust your dose or suggest an alternative medication.

Should that not be possible, treating the issue can often be accomplished by using creams and or ointments.



Some of these may contain steroids, urea, or other compounds that help heal the skin. It is also important to minimize sun exposure as this may exacerbate some of these conditions. When outside, be sure to use sunscreen with adequate protection, and also if possible, cover your skin with clothing so as to further reduce exposure. In colder climates (such as winter) realize that in addition to the sun, wind may also become an issue. Protect yourself from the wind and also wear moisturizer if you can, to reduce your skin drying out.



CRAMPING/ MUSCLE CRAMPS

Cramping and muscle cramps are similar sensations but occur in different locations of the body. Cramping can occur anywhere, including internally, such as in the stomach or intestines (and may lead to diarrhea). Muscle cramps occur in the muscles themselves, often in the extremities. Both types of cramping could be a result of dehydration, and might benefit from increased intake of fluids, including electrolyte replacement beverages like Gatorade.

Muscle cramps are due to a mineral imbalance. Often calcium or magnesium are the culprit, and sometimes vitamin D. In the case of Gleevec patients, both overly high and low levels of phosphorous have been noted. Having these levels checked by a doctor might be a good idea if that is suspected. It is also important to observe whether your activity levels have changed to see if that is the more likely cause (such as recently starting an exercise program or engaging in a physical activity new to you).

One interesting trend that has been observed in the LRG Patient Registry is that muscle cramping is a side effect more frequently reported by males than

females. This occurs independent of age.

While we are not sure of the exact reason for this at this time, it suggests some interesting concepts from a research perspective. How do side effects vary across different factors such as gender or age? Perhaps side effects treatment programs should take that into consideration.



EDEMA

Edema, or swelling, is brought about by fluid retention. Edema can occur throughout the body. For GIST patients this often occurs around the eyes (known as periorbital edema) so we will address that in the next section under eye issues. Edema can lead to further complications, such as shortness of breath, and in rare cases can travel to the lungs which is more severe. Many patients experience edema temporarily, and often that can be treated by dietary changes (i.e., reducing your salt intake and caffeine, and eating more fiber and potassium). In cases where it lasts for longer periods of time, medications like diuretics may be needed, and you may also be advised to limit standing for long periods of time, and elevating your feet (in the case of edema in the feet or legs).

What's most important is being aware of any changes. If you see that you are gaining weight (especially if it looks like it's "puffy" water weight) and you haven't increased your food intake and/or decreased your activity levels, it is best to play it safe and notify your doctor. This will help your doctors get ahead of any issues that may arise if you wait too long to deal with the edema. Interestingly, while muscle cramping is predominately reported by males, edema is predominately reported by females, particularly those over the age of 50. Again, this suggests ramifications for side effect management, and in this case those ramifications extend beyond gender but to age as well.



EYE ISSUES

If GIST patients were to pick one side effect that is most associated with their disease, and particularly those taking Gleevec, high on the list would be eye issues.

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Patients often even refer to this as “Gleevec eyes”, which shows just how prevalent it is. It’s characterized by puffiness or swelling around the eyes, and occasionally eye bleeds. For many but not all patients, it tends to be worse in the morning.

While many patients simply “deal with it” and don’t treat this side effect, topical

solutions and antihistamines have been used by some and have provided various degrees of relief.

One thing to note about our observations in general is that patients often report that their side effects reduce in severity over time. Whether this is due to an actual reduction or just the patient learning to cope with it better and then perceiving it as more tolerable is still an open question.

In any case, managing side effects is a better strategy than simply ignoring them, or taking medication irregularly. Beyond what we’ve offered here, there are a number of resources you can use including the LRG Patient Registry itself. If you are currently a member and are dealing with a side effect and would like some guidance, please reach out to the LRG Registry Staff. They have a great deal of experience dealing with side effects. If you are not currently a member, please consider joining. In addition to having access to the aforementioned help, the data you provide about your side effects helps us learn more not only about what side effects patients are experiencing, but also the interventions they are using to treat them. This helps your fellow GIST patients as we are able to share what we learn in articles such as this one and on our website.

Another resource worth exploring is GIST Chat, which is a chat system limited to LRG patients and caregivers that can be used to discuss a number of topics, of which side effects is one of the most frequent.



Flu Season 2021

- Mary Garland, Director of Communications

Fall is finally here, and with it comes the onset of Flu Season. Flu is a difficult illness for everyone, but for cancer patients, it can be devastating. It is especially confusing in this year which continues to challenge everyone with the uncertainty of COVID-19 and its variants. It is important to recognize that as cancer patients, important healthcare preventative actions like receiving a flu shot should not be ignored. Healthcare providers continue to practice precautions to assure safety during this pandemic.

Always consult your physician before getting vaccinated. There may be certain individual medical contraindications to being vaccinated, and they can recommend a safe source where you can receive the vaccination.

The CDC estimates that flu has resulted in between 9.3 million and 49 million illnesses each year in the United States since 2010.¹

Although there is no way to predict the severity and length of an individual flu season, it is important for GIST patients to receive vaccinations as early as possible. Flu activity peaks between December and March in the United States. The CDC recommends that cancer patients as well as close family members be vaccinated by the end of October.



Important information about the flu:

The flu shot is a seasonal vaccine. Each year it is designed to combat strains of flu expected to cause illness in the current season. Being a cancer patient puts you at an increased risk of complications, which can include pneumonia, hospitalization and even death.

Choosing to get a flu shot is your best protection against the flu.

The Centers for Disease Control (CDC) is the authoritative source for information on the current 2021-2022 season, but as always, it is important for you to check with your individual healthcare provider for any individual restrictions.

The **CDC website** includes:

- A list of the viruses the 2021-2022 vaccines protect against.
- Types of vaccines recommended for protection against these viruses
- Information on updates to the vaccines for this season
- New vaccines licensed for this season
- Recommended vaccines for this season

This site also includes extensive information about COVID-19 and seasonal flu.

One frequently asked question is:

“Is it safe to get a flu shot at the same time I get my COVID-19 booster shot?”

The answer from the CDC is yes. For more info visit the **CDC website**.

When should someone get the flu shot?

September and October are generally good times to be vaccinated. Ideally, everyone should be vaccinated by the end of October. Adults, especially those older than 65, should not get vaccinated early (in July or August) because protection in this group may decrease over time. Children can get vaccinated as soon as vaccine becomes available—even if this is in July or August. Some children need two doses. For those children it is recommended to get the first dose as soon as vaccine is available, because the second needs to be given at least 4 weeks after the first. Early vaccination can also be considered for people who are in the third trimester of pregnancy, because this can help protect their infants during the first months of life (when they are too young to be vaccinated).

More information for vaccination timing can be found here on the **CDC website**.

To learn more about flu (influenza), see this **FAQ**.

For more information on where you can get a flu vaccine, visit: <https://www.vaccines.gov/>

CDC Website: :

<https://www.cdc.gov/flu/season/faq-flu-season-2020-2021.htm>

Talk to your physician and make an appointment for your flu shot today!

Resources

¹ <https://www.cdc.gov/flu/about/burden/index.html>

² <https://www.cdc.gov/flu/season/faq-flu-season-2020-2021.htm>

A Conversation with a Few of Our Global GIST Mentors

- Diana Nieves, Senior Director, Outreach & Engagement

I am excited to announce the expansion of our GIST Mentor program to include our international community. In June 2021, we trained seven LRG members from Austria, Canada, Chile, India, and Singapore. LRG's Global GIST Mentors are survivors or caregivers who volunteer their time, energy, and talent to support others. Mentors offer their mentees understanding and empathy and reassure patients and their caregivers that they are not alone in their GIST journey.

On September 29th, Piga Fernández, LRG Global GIST Consultant and GIST Mentor from Chile, and I presented the LRG's Global GIST Mentor Program to the SPAEN (Sarcoma EuroNet) community during a Coffee Chat webinar. I shared the mission of the program, requirements for volunteers to become a GIST mentor, what a GISTer or their caregiver need to do to connect with a mentor and how successful the mentor program has been for the GIST community. Piga shared her personal experiences as a GIST Mentor and how she helps other GISTers with emotional support, advocacy assistance and education along their GIST journey.

Piga and I also joined other Global GIST mentors on Thursday, October 7th for our LRG Conversations with the Global GIST Mentors webinar. Speakers included Hazel McLeod of LRG Canada and Amelia Yeo, LRG Representative from Singapore. Each shared their GIST journey and why they chose to become a volunteer GIST Mentor.

Piga said that during meetings and events so many GISTers want to connect with someone who is like them and has walked in their shoes. Piga wanted to give back and be that person that assists GISTers. She went from going through misdiagnosis and other life-altering circumstances to connecting with the LRG and receiving the resources she needed to thrive.

"I was diagnosed a long time ago when very few people knew about what GIST was and I felt at the beginning it was really hard to have a cancer diagnosis but even more, having this rare type of cancer that no one knew much about," said Piga.

Piga went through a very hard time and says she didn't want to know anything about the disease, she just wanted to take her pills and get on with her life. Eventually her curious nature sent her to the internet to find out more about GIST and she discovered the Life Raft Group.

"It was really great knowing that someone else had GIST and there were people who knew what this was about and could answer my questions. In this new role as a Mentor I saw the importance of this Mentor Program because we are reaching people all around the world," added Piga.

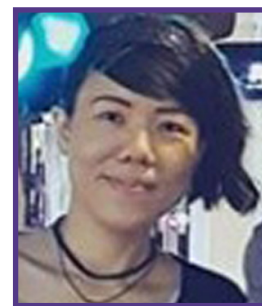
What she learned along her path as a volunteer for the LRG and for Fundación GIST Chile is that while events, webinars, meetings, and support are important for patients and caregivers, the one-on-



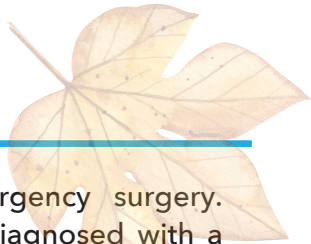
Piga Fernández, Chile



Hazel McLeod, Canada



Amelia Yeo, Singapore



one moments spent relating to someone in a similar situation during the breaks were crucial for patients and caregivers. There was definitely a need for peer-to-peer conversations.

Hazel described how she wants to help people along their journey to find accurate information. She wants to help people to understand and explore all treatment options, encourage them to ask questions, and give them hope knowing they are not alone.

When Hazel was newly diagnosed, she gathered a lot of information about GIST and really wanted to discuss all this information with someone and though her husband was a great support she says she wanted to go over the facts again and again with someone who was 'in her shoes' and who understood her feelings, and be encouraged on her journey from that perspective. Connecting really changed her journey. She got involved in the LRG Canada Sarcoma Group and soon realized she wanted to be that person that someone could come to, to share hope, know that they are not alone, and what options you have during this journey.

"Even when you get to the most difficult challenges in your journey, you are not alone," shared Hazel, "There are those of us that want to come up alongside of you, to talk with you, and help you work through."

Amelia expressed her desire to share whatever GIST knowledge and information she possesses with as many patients and caregivers as she can. As a caregiver, the most important advice that she can share with the same is that they practice good self-care.

A former piano teacher, Amelia's husband Andrew was suddenly rushed to the hospital two years ago, where they found a huge mass on his intestine

which was removed with emergency surgery. After the initial shock of being diagnosed with a GIST, Andrew was in good hands with his medical team, who gave them information. The couple did research on their own, but it was still a lot to process. After the shock passed, they joined GIST support groups and eventually found and joined the LRG.

"Some things you cannot learn by reading. Some things you want to learn or hear from other patients and caregivers themselves. I was so lost in the beginning," Amelia said, "I was shown so much kindness and compassion and given so much support, I wanted to give back. I wanted to offer the same to others."

"We receive a lot more than what we give...the gift is in helping someone to shift their perspective of what they are going through. We get to help someone go from a dark place to a lighter one at the end."

- Piga Fernández

As an LRG representative in Singapore, Amelia

helps others through Asian GIST support groups on WhatsApp and began as an LRG Global Mentor recently. "Knowledge is important in the beginning. We have a few caregivers in this group, but we have mostly patients right now. As a caregiver you must make sure that you yourself are being taken care of first so that you can take care of your loved one."

Diana, Piga, Amelia and Hazel shared these thoughts and expanded on more in our webinar, LRG Conversations with Global GIST Mentors available on our Youtube channel (<https://youtu.be/OznGlbT6OO0>) You can also hear an extensive question and answer time that will illustrate more about how our Global Mentor Program works.

If you would like to become an LRG GIST Mentor or connect with a Mentor, please contact Diana Nieves, Senior Director of Outreach & Engagement, at dnieves@lifteraftgroup.org.

Into Each Life Some Rain Must Fall...and Other Infuriating Platitudes

- Mary Garland, Director of Communications

There is a famous poem by Henry Wadsworth Longfellow, entitled The Rainy Day, which seems appropriate for recent times.

*The day is cold, and dark, and dreary;
It rains, and the wind is never weary;
The vine still clings to the mouldering wall,
But at every gust the dead leaves fall,
And the day is dark and dreary.*

*My life is cold, and dark, and dreary;
It rains, and the wind is never weary;
My thoughts still cling to the mouldering Past,
But the hopes of youth fall thick in the blast,
And the days are dark and dreary.*

*Be still, sad heart! and cease repining;
Behind the clouds is the sun still shining;
Thy fate is the common fate of all,
Into each life some rain must fall,
Some days must be dark and dreary.*

Yes. Some days are dark and dreary. Especially over the past few months, when there have been many weather events that have brought everything from tornadoes to hurricanes and floods around the globe. For some, that has meant being without power and bailing out basements. For others, it has meant the loss of their homes and businesses, and in some cases, a loss of life.

How do you handle the “dark and dreary” days? Do you take a stiff upper lip approach, and “Keep Calm and Carry On?”, or do you allow yourself to jump headlong into experiencing the darkness.

Each individual’s approach to adversity is unique. It is a valuable however, to examine how you handle difficult things to be able to identify if there is a more helpful approach. This is especially true for cancer patients.

First of all, it is vital that you recognize that it is 100% normal to feel upset when difficult things happen to you. Especially if those things are out of your control, like a cancer diagnosis. Like a hurricane.

It is important to validate your feelings about each challenge you face. One of the best ways to do this is to have a support person or group with whom you are comfortable expressing how you really feel. This is the friend or spouse who allows you to kick and scream to express your anger, or to cry rivers of tears to mourn a loss. Or maybe it is a group of friends who have suffered the same loss that you have and understand your feelings, or a support group from a trusted organization.

The next thing to do is to separate the “wheat from the chaff” by identifying which parts of “the dark and dreary” are within your control, and which parts are not. We can’t control a cancer diagnosis once it has been verified, but we can control how we advocate for ourselves moving forward.

We can build a support team, learn everything we can about our disease, choose the best specialists to care for us and make informed decisions. If we hit roadblocks to that optimal care, we can reach out to helpful support systems like the LRG to help us navigate our journey.

Part of that support team can be those caring people who will listen and stand by us on those dark days. If it is part of your nature to look, as Longfellow does, for the sun behind the clouds, your team can validate that. If you take a darker view, they will help you recognize it, and be with you until it passes or you seek help to get through it. Do not dismiss professional help as part of your team. Let everyone know what you need once you identify it for yourself.

Recently, when experiencing the aftereffects of Hurricane Ida’s rampage through our area, someone I know posted on Facebook that as she was spending hour after hour bailing out water from her home, she did not want to hear platitudes like “it could be worse” or “this too will pass.” She was courageous enough to let people know what was helpful and what was not. When I experienced a similar flood event, what mattered most were the three friends who showed up to help me with clean up. No platitudes, no easy answers, just elbow grease. But if you are someone who needs the inspiring words, and the encouragement, let your support team know.

There is no right way to get through a “rainy day,” but there is a way that will work for you. The sun is shining today, but I think I’ll make a plan so that when the next rainy day comes, I will know where to go to look for the sunshine.



Total number
of patients in
registry

2412



52%

Female



48%

Male

55%

of our patients
know their mutation

If you do not know your mutation or have not had mutational testing* (a type of biomarker testing), we are offering at no cost for eligible patients. For more information email Denisse Montoya at dmontoya@liferaftgroup.org

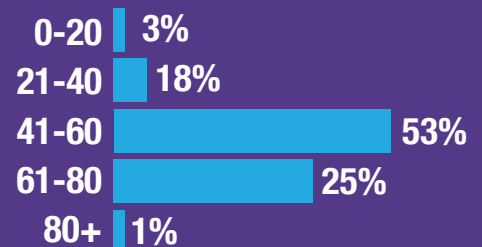
Country of Birth

U.S.
69%



International
31%

Age at Diagnosis



**We offer free mutational testing.
Contact the LRG today.*

Become an LRG Member & join our active chat forum GIST Chat to get peer support and conversation about GIST. Hear other GISTers' and caregiver stories.

<https://liferaftgroup.org/life-raft-group-membership-application-form/>

Your data matters to GIST Research!

Become a member of the LRG GIST Patient Registry today and be a part of the largest GIST Registry in the world. Everyone's help gets us one step closer to more treatments and a cure. Contact our Patient Registry department at: patientregistrydepartment@liferaftgroup.org



Advocacy in Action *Notes from Down Under*

GIST Patient Advocates have won another battle in Australia. We previously shared the story of these advocates who banded together to assure that patients would have access to newly approved drug, Qinlock.

Though they were an integral part of having Qinlock (ripretinib) approved for use by the TGA (Therapeutic Goods Administration) of Australia in July of 2020 as a 4th line treatment for adult patients with advanced GIST, patients who were eligible would have faced paying full price for the costly drug. For those patients in need this delay in coverage affected access to a lifesaving treatment. Australian GIST patients/advocates and medical professionals fought to change this.

On August 20, 2021, GIST advocate Sarah McGoram shared these results on social media:

"We did it! The PBAC (Pharmaceutical Benefits Advisory) recommended funding of Qinlock on the PBS (Pharmaceutical Benefits Scheme) for GIST."

QINLOCK was added to Specialised Therapeutics' pre-PBS Listing Access Program and made available to eligible Australian patients at no charge as of October 13, 2021. ST cited that the decision was made "due to strong patient demand and the high unmet need for patients with advanced GIST."

All patients enrolled in the program need to meet all of the proposed PBS criteria, which includes: "for the treatment of adult patients with metastatic or unresectable gastrointestinal stromal tumors (GIST) who have progressed despite prior treatment with imatinib and sunitinib". It will enable patients to transition from the access program to PBS-subsidized therapy when QINLOCK is formally listed.

"This is another win for Australian GISTers and one that I'm so happy to be sharing with you all now" stated advocate Shari Reid.

Thank you to our major donors June, July, August & September

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Monthly Virtual GISTer Support Group

First Tuesdays Each Month
6pm-7:30pm ET

Virtual Caregeiver Support Group

1st & 3rd Wednesdays Each Month
1pm-2:00pm ET

New Member Orientation
First Thursday Each Month
8am & 12pm ET

UPCOMING VIRTUAL WEBINARS

Perspectives in Biomarker Testing
October 28 - 1pm ET

Caring for the Caregiver
November 2 - 12pm ET

Immunotherapy in GIST
November 18 - 1pm ET

GDOL NY-NJ - Virtual
November 6 - 10am-12pm ET

GDOL Arizona - Virtual
December 2, 4pm PT

GDOL Pittsburgh - Virtual
December 11

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