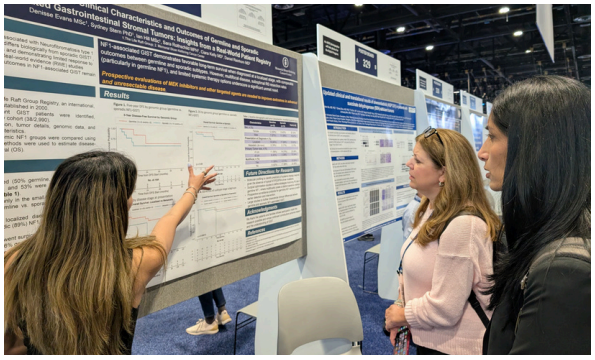
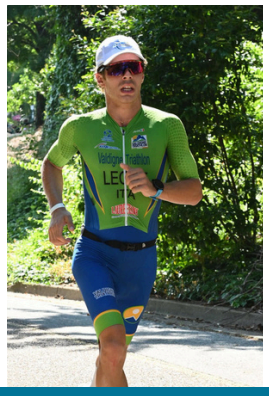
The Life Raft GROUP

JULY 2026 NEWSLETTER


Navigating Rare Together

Empowering Patients Living with GIST

DONATE

The Life Raft Group is committed to enhancing the survival and quality of life for people living with Gastrointestinal Stromal Tumor (GIST), and other rare diseases, through patient-powered research, education and empowerment, and global advocacy efforts. Our vision is to empower a future fueled by data, guiding our journey toward cures for rare diseases.

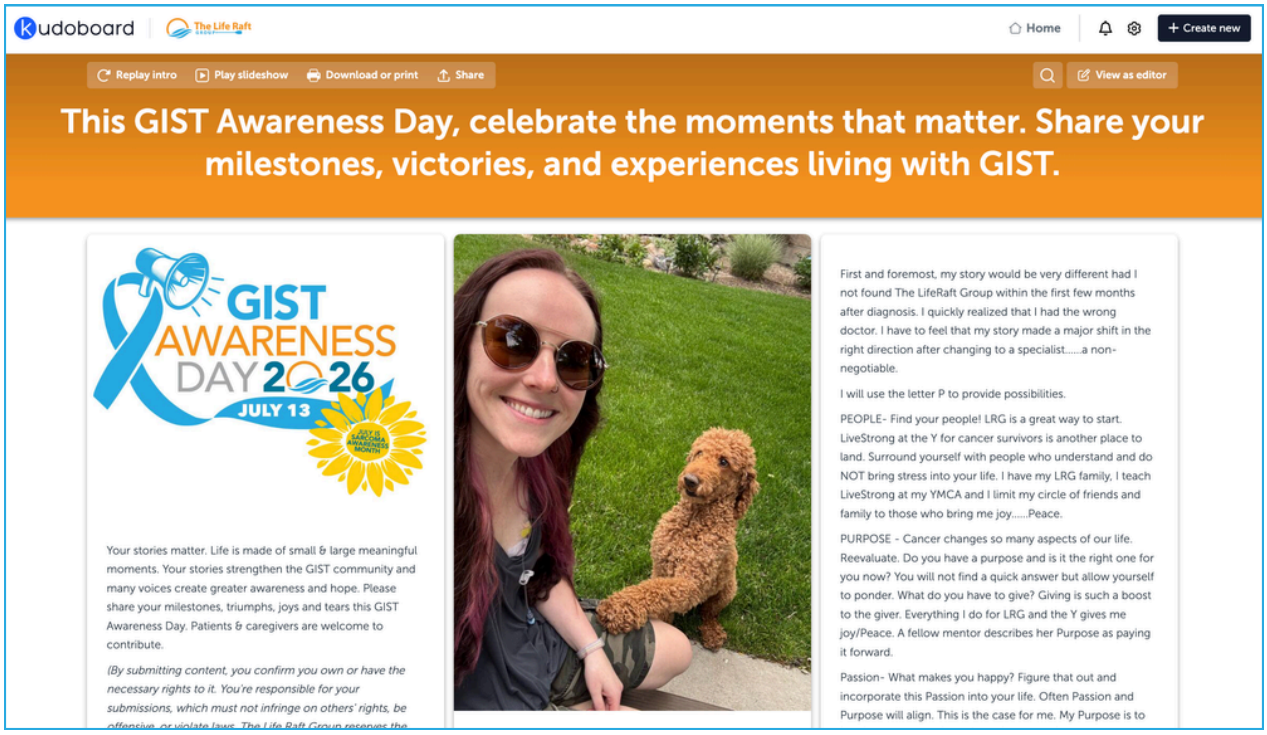
July is Sarcoma Awareness Month and if you follow our social media online, you'll see many opportunities to share information about GIST throughout the month. We also encourage you to share your story this month and on GIST Awareness Day (July 13th) - your milestones & trials, triumphs & joys on our public kudoboard. These posts show our community that no one needs to be alone living with GIST and that surviving can be thriving even when dealing with a rare cancer.

Your voice matters when encouraging and supporting others and also in GIST research. Every data point - whether it's referring to quality of life or side effects of treatment helps move research forward toward a cure. This month our Data Management & Research team will be unveiling a new patient-friendly LRG Patient Registry which will benefit you in real time and research in the long run. Stay tuned for the big reveal at Life Fest and the followup posts on exactly what this means for the GIST community.

This month's newsletter is packed with patient stories, ASCO research updates and conference travel thoughts, with highlights of the Pediatric SDH-Deficient GIST NIH Clinic as well as many other tidbits of what The Life Raft Group is doing to help our community thrive & survive.

One of the best parts of this community is getting to share your stories. If you have a milestone, a personal update, photos from an event, or a story that could inspire others, please send them to us. We love highlighting the many voices that make our community so special. Email Carol Tordella at ctordella@liferaftgroup.org

GIST Awareness Day is July 13th!



Be encouraged and encourage others during Sarcoma Awareness Month (July) and bring awareness to this rare disease!

Your voice matters when encouraging and supporting others and also in GIST research. Every data point - whether it's referring to quality of life or side effects of treatment helps move research forward toward a cure. This month our Data Management & Research team will be unveiling a new patient-friendly LRG Patient Registry which will benefit you in real time and research in the long run. Stay tuned for the big reveal at Life Fest and the followup posts on exactly what this means for the GIST community.

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Featured Articles:

Are You Ready for a New Patient Registry?

by Rebecca Pauley, Director, Programs

A NEW LRG Patient Registry is launching soon! For more than two decades, the LRG Patient Registry for GIST has been integral to advancing our mission to improve outcomes for people living with gastrointestinal stromal tumors (GIST). Our LRG Patient Registry has been utilized by researchers for countless research studies and has represented the idea that patient-reported outcomes is the future of science and cancer research.

Today, over 25 years later, we are proud to introduce the next chapter in that legacy.

After years of planning, collaboration, and countless hours of development, we are launching a completely reimagined LRG Patient Registry. The registry has been completely rebuilt with the future in mind and provides a modern, intuitive experience for patients while creating a more powerful platform for researchers working to answer some of the most important questions in rare cancer.

As GIST researcher and oncologist Michael Heinrich shared at ASCO 2026, “It’s like doing a jigsaw puzzle, and you only have some of the pieces. You might not be able to figure out what the picture is. If you have more pieces, it will become more clear.”

This new patient registry will put the puzzle pieces together, faster and more efficiently than ever before because patients cannot wait

Built by the Community, for the Community

Creating this registry has been one of the most ambitious projects in our organization’s history.

Our staff worked alongside software developers, researchers, clinicians, patient advocates, and, most importantly, patients to design a platform that reflects the real needs of the GIST community. Every feature was carefully considered with one goal in mind: making it easier for patients to participate in research while generating higher-quality data that can accelerate scientific discovery.

So, What's New?
The redesigned registry introduces a variety of new features that make participation easier than ever before.

Participants will be able to:

- Find clinical trials that may be relevant to their diagnosis.
- Upload medical records and supporting documents quickly and securely.
- Track symptoms, treatments, and side effects over time.
- View a personalized health timeline.
- Complete surveys through a streamlined, mobile-friendly interface.
- Update medical information more easily as their journey evolves.
- Participate from virtually anywhere using computers, tablets, or smartphones.
- Receive a more personalized experience with improved navigation and simplified questionnaires.

Behind the scenes, the platform also offers significant improvements in data quality, security, and research capabilities. Enhanced analytics, standardized data collection, and improved interoperability will help researchers identify trends more quickly and generate meaningful insights from patient-reported data.

Why Patient Registries Matter
For common diseases, researchers often have access to large datasets collected from thousands or event millions of patients.

Rare cancers are different; there are less patients with the specific cancer and they are spread across the world, so gathering enough information to answer critical research questions can be incredibly challenging. Patient registries bridge that gap by bringing together experiences from individuals regardless of where they receive care.

Over the years, the LRG Patient Registry has contributed to numerous scientific publications, informed clinical guidelines, and helped researchers better understand treatment patterns, mutation types, and patient outcomes. The registry has become one of the world's most valuable sources of real-world GIST data.

With this new platform, we hope to build on that legacy.

Looking Toward the Future
This new registry is designed not only for today's research questions, but for tomorrow's discoveries.

Its modern architecture allows us to incorporate emerging technologies, including artificial intelligence and advanced data analytics, to help identify patterns that might otherwise go unnoticed. As the registry grows, these tools have the potential to accelerate hypothesis generation, support precision medicine, and provide researchers with new ways to understand GIST.

Just as importantly, the platform was intentionally designed to be scalable.

Our vision extends beyond GIST. We believe this model can serve as a blueprint for other rare disease communities seeking to build high-quality patient registries that empower patients and advance research. By creating a flexible, adaptable platform, we hope to reduce barriers for other organizations and help accelerate research across multiple rare diseases.

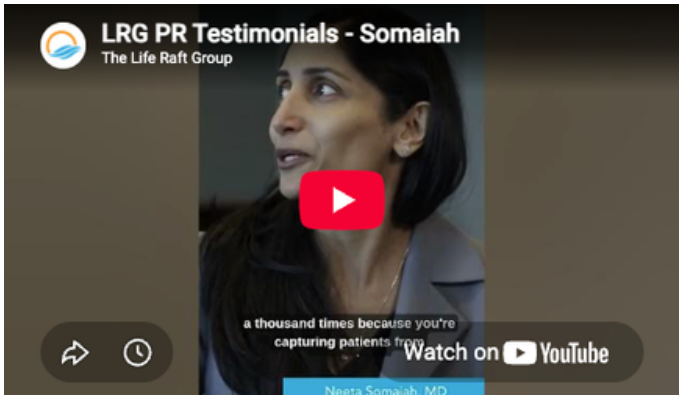
The recent expansion of The Life Raft Group's mission to include liposarcoma is just the beginning. This platform positions us to support additional rare disease communities in the years ahead while maintaining the same commitment to patient-centered research that has defined our organization since 2002.

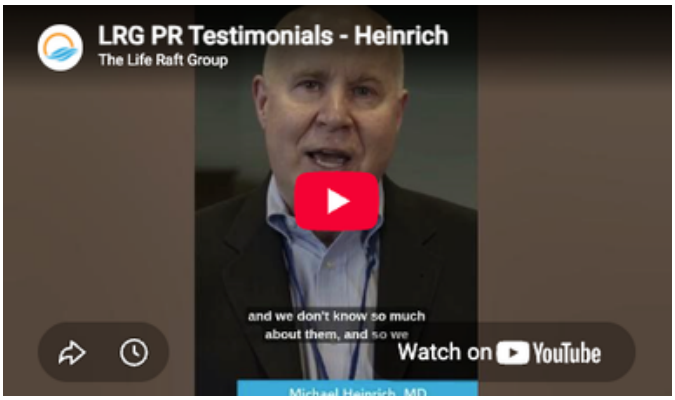
Thank You
None of this would have been possible without the dedication of our patients, caregivers, physicians, researchers, partners, and supporters.

Most of all, we want to thank every registry participant. Your willingness to share your journey has fueled discoveries that have changed lives, and your continued participation will help shape the future of GIST research.

The future of rare cancer research starts with patients. And thanks to this new registry, that future has never looked brighter.

LRG Medical Advisory Board Members talk about the importance of Patient Registries for GIST research.





Getting Involved in a Clinical Trial for GIST

by Rowen Seykora, LRG Volunteer

The ongoing search for better methods of disease prevention, diagnosis, and treatment is carried by clinical trials.[1, 2] Gastrointestinal stromal tumors (GIST) were identified as a distinct group of sarcomas in 1998.[3] Since then, research has helped doctors and scientists gain a deeper understanding of GIST, leading to more precise ways of treating this rare cancer.[3,4,5] These evolved standards of care have greatly improved patient outcomes.[4,6]

Presently, there are many active trials for GIST, and new ideas are being explored to this day. Researchers and participants alike aim to increase available treatment options, develop better ways to address less common molecular subtypes[2,5], and manage treatment resistance.[7]

Category of study	How is it conducted?	How is data obtained?		
Observational Studies	Strictly watch participants to learn about health outcomes	Can either be	Retrospective	Looks at past or historical data to understand health outcomes[10]
Interventional Studies	Offer an experimental aid or care plan to participants to test it[9]	Can only be	Prospective	Looks at present findings in real time to understand a disease

Because interventional studies involve researchers giving patients an experimental health measure, by nature, they can only be prospective, or occuring in the here-and-now.[9]

When most people think of clinical research, they picture an *interventional clinical trial.* In interventional studies, participants are given an experimental aid.[9] This may be a new way to diagnose a disease, a prevention strategy, or an investigational treatment, such as a drug. Studying an intervention in real time helps researchers evaluate its safety and efficacy.[1,9] In other words, this shows us whether the proposed aid can improve the outcome of a disease without a steep risk of unbearable or life-threatening side effects.[9]

Over the past two decades, clinical research has elevated the standard of care for GIST. Contemporary trials have explored combination therapies,[11,12] sequencing to guide more precise treatment approaches,[5,13,14] and more recently, strategies like immunotherapy, which helps the body's own immune system better fight cancer cells.[15,16]

What is the clinical trial process like?
Discovery of possible treatments often starts in the laboratory. This stage is sometimes called pre-clinical development. Here, the goal is to gather evidence that the potential therapy could be effective and safe, usually by testing it in human cells or animals.[2,8] This evidence is examined by regulatory or ethics groups, such as an Institutional Review Board (IRB). These groups then determine if the proposed treatment advances to a trial.[8]

Clinical trials represent the next series of steps: where the most promising ideas are tested for their ability to practically aid in a human health challenge.

Trials for a rare disease, such as GIST, usually have fewer participants by nature.[17] This presents unique challenges: trials must generate accurate findings with a smaller sample size, while also prioritizing ethical access to experimental treatments. Alongside modern, flexible study design, rare disease trials may sometimes combine phases to accelerate the process and help retain patients.[17,18] These types of trials for GIST have seamlessly moved promising treatments through stages of investigation more quickly.[19] **Coordinating clinicians and trial staff are able to provide more detailed information about a trial's specific design and the advantages and considerations that come with it.**

As a treatment progresses through each stage of a clinical trial, participant safety remains a priority. Researchers must submit a plan, formally called a protocol, that outlines the intended treatment, safety measures, and other parts of the trial's design. Additionally, ongoing oversight reduces unnecessary risk to patients and volunteers. This supervision also helps make sure that the study's findings are accurate and based in sound medical science.[2,8]

Is a clinical trial a good option for me?
A common misconception is that clinical trials are only recommended to patients who have gone through all other options. However, it is important for all GIST patients to explore all treatment options, including clinical trials, before deciding on a treatment path. Exploring these options gives patients several benefits:

1. Access to the latest treatment options. Clinical trials may provide access to promising new therapies that are not yet widely available and could offer benefits beyond current standard treatments.
2. More informed decision-making. Reviewing all available options, including approved treatments, surgery, watchful waiting, and clinical trials, helps patients understand the potential risks, benefits, and goals of each approach so they can choose the path most aligned with their needs.
3. Keep future opportunities open. Some clinical trials have specific eligibility requirements, and certain treatments or procedures may make patients ineligible for a trial later. Reviewing clinical trial options early can help ensure you understand how today's treatment decisions may impact future opportunities.

Lastly, many participants express the desire to join a clinical trial to take part in improving our collective understanding of a disease.

Clinical research participation also comes with some considerations. While there are serious measures in place to safeguard participant wellbeing, participation can involve some risk. Experimental treatments may cause side effects or, in rare cases, life-threatening complications.[2]

Trials may also demand a greater time commitment from participants compared to standard treatments. Logistic factors such as rigid medication schedules, appointment frequency, and distance from a research center can all be real barriers.[20] The educational and informed consent documents given to participants are designed to address these possibilities and help patients make the best decision for their unique situation. Trial coordinators can provide information about study goals, safety, duration, and more.

For a first-hand point of view of these considerations, The Life Raft Group hosted a recent webinar featuring patient and clinician perspectives on the trial process.

Where can I learn more about getting started?
Patients are encouraged to seek ongoing education about clinical trials and to check regularly for updates. New trials begin enrolling regularly, and just because there may not be a trial that's a great fit for a patient now, that doesn't mean a better option won't become available in the following months.[20]

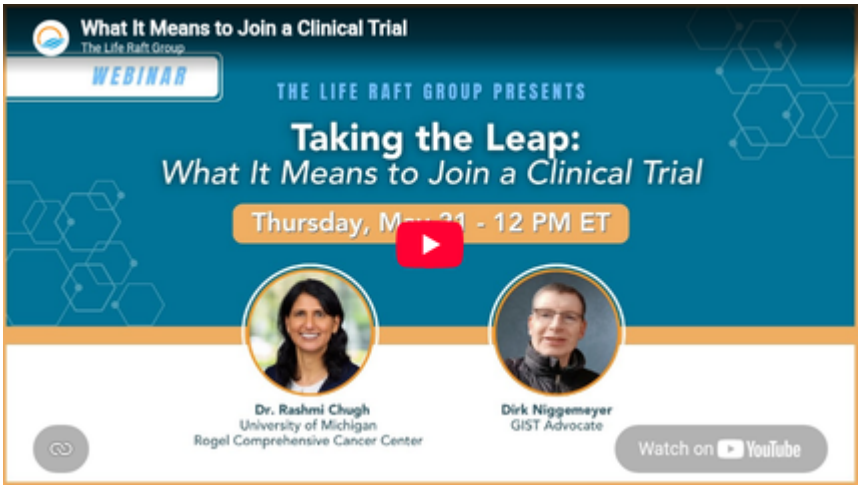
If a patient does not qualify for an active clinical trial, but wishes to explore alternative treatments, expanded access programs (EAPs) can be another option.[21]

As the name suggests, EAPs exist to increase access to medical interventions, offering experimental treatments to a wider group of patients with immediate need.[21] They are suggested when a patient is in serious condition, is unable to participate in a relevant clinical trial, and has gone through all other approved, or standard, treatments. Still, these programs must protect participant safety, and they are strictly offered when the benefit of the experimental aid is expected to outweigh the risks. It is also important to consider that an expanded access option may not necessarily be available for every investigational treatment that is actively being tested in an ongoing trial.[21]

There are online resources available to patients and loved ones, designed to streamline the process and connect participants with the active trials most relevant to them. The GIST Clinical Trials Database is a free, curated list of opportunities. Lastly, connecting with a GIST specialist is a great way to learn more about trials that might be a good fit.

Having up-to-date information is the first step to considering a clinical trial. The Life Raft Group is able to provide resources, answer questions, and connect patients to a specialist who can help.

WATCH NOW: Dr. Rashmi Chugh from the University of Michigan Health Rogel Comprehensive Cancer Center presented on how clinical trials work, who they are for, and what patients can really expect, plus, Dirk Niggemeyer, a GIST patient, shared his personal journey navigating two clinical trials.



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Living Well with Sarcoma – Exercise & Nutrition

by Mahak Gupta, LRG Volunteer

Practical Lifestyle Habits for Everyday Life

Living with sarcoma often means learning to navigate life alongside ongoing treatment, regular scans, side effects, and uncertainty. Even during periods of stability, fatigue may linger. Eating may feel different. Strength and stamina may not be what they once were. These challenges are real, and they are common.

The good news is that small, everyday habits can help support quality of life. The Life Raft Group recently hosted a webinar with an Dr. Loren Yavelberg, Exercise Oncology Specialist and Dr. Harleen Kaur, Nutritionist, both from the University of Miami to help explain how you can find realistic ways to feel stronger, more supported, and more like yourself while living with sarcoma.

Nutrition: Build Habits, Not Rules

Healthy eating does not mean following a strict diet. It means building simple habits that fit your everyday life. Dr. Kaur stressed that there is no single “best” diet for every patient. Instead, individuals should focus on creating a sustainable eating pattern that works for their specific health needs and lifestyle. Dr. Kaur encouraged participants to build balanced meals by “filling half of their plate with vegetables while incorporating adequate protein, whole grains, healthy fats, and colorful fruits and vegetables”. Consistency, rather than perfection, was emphasized as the key to long-term success.

Treatment side effects can sometimes affect your appetite or digestion. If this happens, try to build flexible habits that work for you right now, rather than chasing a perfect plan. Small routines also help. Prepare meals ahead of time, keep healthy snacks nearby, and eat at regular times each day. The goal is not perfection. It is finding a pattern you can keep up over time.

Communities known as “Blue Zones,” where people often live long and healthy lives, offer a simple reminder that everyday habits matter. During Life Raft Group’s webinar, Dr. Yavelberg referenced the popular documentary Live to 100: Secrets of the Blue Zones and described how researchers have identified several common lifestyle patterns among populations in places such as Okinawa, Japan; Sardinia, Italy; and Loma Linda, California.

According to Dr. Yavelberg, these communities share many of the same principles emphasized in lifestyle medicine. “They eat wisely. They have a connected mentality. They move naturally and they have a positive outlook with a general purpose,” he explained. Rather than relying on structured workouts alone, many individuals in these regions stay active through daily activities such as gardening, walking, and completing household tasks by hand. People in these communities tend to eat mostly plant-based foods, stay active, and focus on consistency rather than perfection.

Physical Activity: Every Move Counts

Dr. Yavelberg highlighted the growing body of evidence supporting exercise as an integral part of cancer care. Research has demonstrated that regular physical activity can improve cardiorespiratory fitness, strength, fatigue, quality of life, and treatment tolerance among people with cancer. Importantly, experts now recommend that cancer survivors avoid inactivity whenever possible.

Being active with sarcoma can feel difficult, especially when treatment, side effects, fatigue, or changes in strength make movement more challenging. But physical activity does not have to mean intense workouts. Walking, stretching, taking the stairs, gardening, household activities, or doing a short resistance session at home all count.

Most health guidelines suggest around 150 minutes of moderate activity each week – about 20 to 30 minutes on most days. Adding some strength exercises, such as light weights or resistance bands, can help keep muscles strong and support daily activities.

Every bit of movement counts, and daily activities can be just as important as structured exercise sessions. Staying active can also help reduce fatigue, build strength, and improve quality of life.” Start at your own pace and build up over time.

Sleep: More Important Than You Think
Sleep problems are among the most common concerns reported by people living with cancer. Poor sleep can affect mood, energy, concentration, and the body's ability to recover.

Sleep is not just about rest – it helps the body recover, supports emotional health, and improves quality of life. Both how long you sleep and how well you sleep matter. If sleep disturbances are affecting daily life, it is important to discuss them with your healthcare team. Making sleep a priority is one of the most effective ways to support overall health and well-being.

Stress Management: Taking Care of Your Mind
Living with sarcoma can bring uncertainty, anxiety, fear of recurrence, and emotional challenges that may continue long after diagnosis. These feelings are common and deserve attention.

Practices such as mindfulness, deep breathing, gentle movement, and spending time on enjoyable activities were highlighted in the webinar as ways to help manage stress. There is no single approach that works for everyone. Finding one or two strategies that feel manageable is often the best place to start. If stress feels overwhelming, speaking with a counselor or joining a support group may also help.

Risky Substances: What to Know About Alcohol
Alcohol is one substance worth taking seriously. Research has linked alcohol to at least seven types of cancer, and it can also disrupt sleep, lower energy levels, and affect recovery.

Dr. Kaur explained that when alcohol is metabolized in the body, it can damage DNA and increase inflammation, both of which may contribute to cancer development and progression. "Alcohol can increase the risk of developing at least seven types of cancers," she noted, encouraging participants to consider how alcohol consumption may affect their overall health and cancer journey.

Alcohol may also worsen sarcoma treatment side effects or affect how some medications are tolerated.

Understanding the risks and making informed choices can support long-term health and quality of life.

Where to Start
There is no need to change everything at once. Start by taking stock of where you are now and what you would most like to improve. Then choose one area to focus on and begin there.

Living well with sarcoma is not about being perfect. It is about building habits that support health and quality of life.

WATCH NOW: In honor of National Cancer Survivors Month, The Life Raft Group hosted an empowering and informative webinar, "Expert Nutrition & Exercise Advice for Sarcoma Patients," on June 1. The session featured Dr. Loren Yavelberg, Post-Doctoral Associate, CEP, ACSM-ACS Exercise Oncology Specialist, and Dr. Harleen Kaur, a behavioral scientist with a PhD in Nutrition Sciences, both from the University of Miami.

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Patient of the Month - July

by Jodi Bachand of Vermont

Jodi's GISTory

My story started in October 2020 when I went to the Emergency Room in Burlington, VT with COVID symptoms. While I didn't have COVID, I was diagnosed with Stage IV GIST, Exon 11, high risk cancer. I had a 9-inch tumor in stomach and a 4-inch tumor which metastasized on my liver. I was confused and shocked when they told me, but my initial reaction was to fight with all my being because I have so much to live for.

My journey had started. I started chemo (imatinib) because we had to shrink the tumors before we could remove them.

By May of 2021, the tumor in my stomach had shrunk enough for my first surgery where they removed the tumor along with 50% of my stomach, my spleen, and 30% of my left diaphragm.

I went home to recover because my second surgery was in September 2021 where they removed the cancer, 40% of my liver, my gallbladder, and a portion of my right diagram. This recovery was harder, and I struggled even more.

I ended up with an internal bleed in November 2021. My doctors in Vermont took me off treatment, told me to go home and get my affairs in order. They didn't know what else to do with me because they only had a hand full of GIST patients in Vermont and mine was the most severe.

I went for a second opinion at Dana-Farber (Boston) in February 2022, which saved my life. My disease is manageable but incurable. My treatment is focused on controlling symptoms and prolonging life. I still take a Chemo pill every day and go to Dana-Farber every three months for scans, treatments, labs and meeting with my medical team. I will do this indefinitely.

How I cope with GIST

First and foremost, I am very faith-based and put my journey in God's hands. I allow myself to feel all of the emotions associated with my disease. I try to be optimistic. I trust my medical team. I engage in activities that bring me happiness, such as spending time with family and friends, listening to music, dancing and spending time with my husband and loyal dog, Clover. And I pray a lot.

My advice to fellow GISTers

I love this question because I wish I had a fellow GISTer to get advice from. Resources in Vermont with regard to GIST cancer were nil. I struggled to find answers or just get advice. So, I wrote a book for the next GIST patient in Vermont (or wherever) who might need a little direction and inspiration. My book, Jodi's Journey: Living with Cancer, is a compilation of journal entries I made the first 18 months of my battle with GIST. My book gives a glimpse of what my journey looked like. I wanted to write a sequel, but it's a lot of work writing and publishing a book, so I started a podcast with two friends, Kind Hearts, Strong Souls, where we continue to talk about our journey. We are currently recording Season 2. My advice is to utilize these two resource. (Check out the podcast here!)

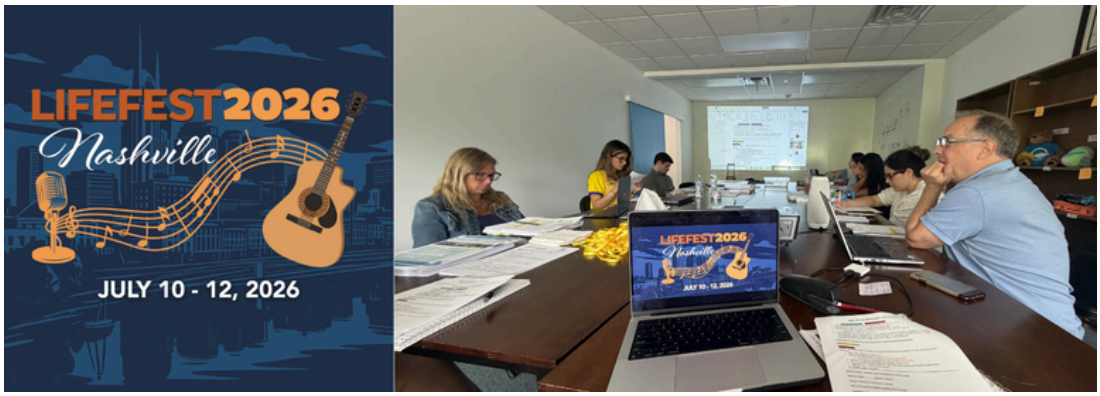
Hobbies I enjoy

I love to crochet! I make sweaters, blankets, hats, scarves, and I like to upcycle clothing with crochet items.

My #GISTLife Motto

"We are living our 'someday' today" (You know how people say "someday I'm going to go to travel, or someday I'm going to retire").

LRG 'On the Road'



The LRG team will be on site in for Life Fest Nashville for a weekend of educational sessions & connection with GIST patients & caregivers. We can't wait to see you there!

CHICAGO

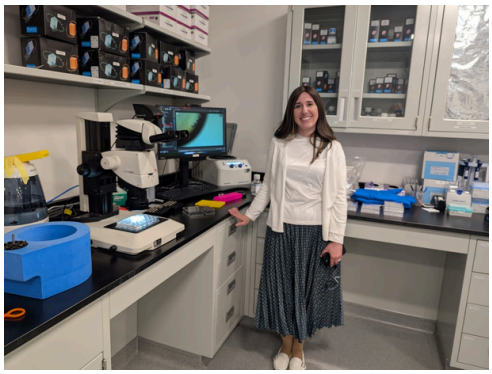
ASCO PHOTO GALLERY

WASHINGTON DC

Registry Consultant Becky Owens shares her experience at this year's NIH Succinate Dehydrogenase (SDH) and Ultra Rare GIST Clinic.

READ MORE...

COLORADO



Executive Director Sara Rothschild visited the Cogent Biosciences labs in Colorado with other patient advocates in June.

Events:

If your weren't able to make Life Fest this year, consider joining us at a free one-day GIST Day of Learning this fall.

GDOL Minnesota
Sept. 26

REGISTER

GDOL San Diego
Oct. 24

REGISTER

Events:

Water of Life

This past June the Water of Life fundraiser brought together whisky lovers from near and far. Thank you to all who attended and made the event memorable, and thank you to our host Dr. Matthew J. Lurin.

VIEW PHOTOS

View Recordings:

Updates from ASCO (video)
(Link to summary post)

Expert Nutrition & Exercise Advice for Sarcoma Patients

What It Means to Join a Clinical Trial
(Trial Investigator & Patient Perspectives)

SUPPORT & CONNECTION

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