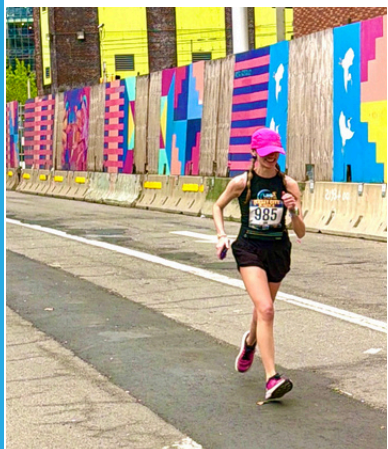


## MAY 2026 NEWSLETTER



## 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.

This month's issue is filled with patient stories, an invitation to #FindYourCommunity at Life Fest, and a celebration of one LRG Athlete's recent accomplishment. We're also taking you behind the scenes to show how The Life Raft Group brings the patient voice to conferences and conversations around the world.

On our upcoming events calendar, we're looking forward to Life Fest in Nashville and the Walk for Hope happening the same weekend. We're also marking National Cancer Survivors Month with a nutrition & exercise for sarcoma webinar on June 1st. And if you missed it, you'll find recordings from the GIST Summit (GDOL) held in Houston this past February.

We're also pleased to share that our Annual Report is now available, offering a closer look at our work, milestones, and organizational progress over the past year. [View Here](#)

This month also marks an important moment in the research world, as the oncology community gathers for ASCO, one of the largest cancer conferences in the world. We'll be watching closely and sharing important GIST updates as they emerge. We are also proud to share that from 8,500 submissions, our poster on NF1-associated GISTs was chosen to be presented at the conference!

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 [ctordella@liferaftgroup.org](mailto:ctordella@liferaftgroup.org)

## ***Featured Article:***

### **From Patient Registry to a International Scientific Conference**

by Denisse Evans, Senior Director, Data Mgmt. & Research

NF1-associated GIST Findings Presented by The Life Raft Group

When our team started looking more closely at NF1-associated gastrointestinal stromal tumors (GISTs), one thing became clear right away: there were far more questions than answers.

NF1-associated GIST is a rare subtype of GIST, which means there is still limited information available about it compared with other cancers and even other types of GIST, such as KIT-mutant GIST. Because of this lack of knowledge, we felt it was important to take a deeper look and learn more about the disease and the experiences of patients living with it.

To do this, we turned to our Patient Registry to learn more. By studying real-world patient data, we were able to better understand the experiences, characteristics, and outcomes of people living with NF1-associated GISTs. But we didn't rely on data alone. We also reached out directly to patients to make sure the information in our registry reflected their most up-to-date experiences. Their participation helped make this research stronger and more meaningful. We then ran multiple statistical analyses and summarized all the data.

Researchers from Memorial Sloan Kettering Cancer Center had also been studying NF1-associated GIST, so we decided to collaborate. Together, we reviewed our findings and prepared an abstract, which is a short scientific summary of the study. An abstract gives an overview of why the study was done, how the research was carried out, what was found, and what the results may mean for patients and future research.

Once we had our findings ready, we submitted them to the Annual Meeting of the American Society of Clinical Oncology (ASCO), one of the largest and most respected cancer conferences in the world. Then we waited while thousands of research projects from around the globe were reviewed.

Out of about 8,500 submissions, ours was selected.

Our research, titled "Clinical Characteristics and Outcomes of Germline and Sporadic NF1-Associated Gastrointestinal Stromal Tumors: Insights from a Real-World Patient Registry," was accepted for an oral poster presentation. This gave us the chance to share what we learned about this rare type of GIST with doctors, researchers, and cancer experts from across the world.

This milestone shows why research into rare diseases matters. It also highlights the power of patient registries. Every patient who shares their experience helps us better understand rare cancers and move research forward.



Your Story Has An Impact on the GIST Community & GIST Research!

[LEARN MORE ABOUT PATIENT REGISTRY](#)

## Patient Stories:

### What 19 Years With GIST Has Taught Me

by Ed Cohen, GIST Advocate

#### Long-Term Survival & Living Beyond the Diagnosis

About a week prior to Father's Day in 2007 I started feeling a little unsettled in my gut. I felt that it was a "bug" of some sort and ignored it for a couple of days. However, on the third day, as it continued, I decided to see my doctor. I only worked a half day and then went home to install a new flat screen TV and move other TVs around. The movement of lifting, twisting and bending may have saved my life.

I ate a light dinner, went to bed, and awoke around 3am needing the bathroom. In the bathroom I fainted twice. My wife and I decided to go to the local ER and made our way downstairs, where I fainted and vomited blood. The ambulance personnel arrived, loaded me on a gurney and transported me to the local ER. An IV was started and a nasal-gastric tube was inserted. Contrast CTs followed later in the day, and after the films were read, my family and I were told there was something in my stomach, with two possibilities and I needed exploratory surgery as soon as possible to determine a diagnosis and course of treatment. I was transferred to North Shore University Hospital in Manhasset, NY

At about 7am on Father's Day, Drs. James Sullivan (abdominal gastric oncological surgeon) together with one of his partners, Dr. Charles Conte (complex general oncological surgery) operated and removed about 20% of my stomach, all my spleen and about 5% of my pancreas (with clear margins). I didn't know it at the time, but this was the beginning of my 19-year GIST journey.

Fortunately, at this same time the FDA had approved imatinib (Gleevec) for adjuvant GIST treatment, and within a month or so I started taking it. Since 2007 I've had three more GIST surgeries (I now have about a third of a stomach, and my omentum and a piece of my colon currently reside in the pathology lab at MSKCC).



TODAY

I was almost 57 years old in 2007 and had no idea whether I would be able to work and earn a living and live my life with my wife and family, who have stood by my side and cared for me during my recoveries. Though my parents were eternal optimists, I am less so but am mostly an optimist. I also lived in proximity to Memorial Sloan Kettering Cancer Center, which at the time was one of five cancer centers in America working specifically on GIST. They had the knowledge, treatment and care protocols from the top doctors and their research into GIST in the lab and it was available to me.

I also had perseverance. I've been able to survive each challenge and move forward using all of the foregoing. Finally, imatinib had just been approved for post GIST surgery treatment, with a second line drug, sunitinib just coming on the scene to stop the GIST from receiving protein, was another factor. So, with this information, this optimist with perseverance, the support of family and proximity to a top-tier cancer center, moved forward. Each surgery was a stumbling block that tried to get in the way of my life. My doctors have given me time and the meds keep the GIST at bay and my optimism, perseverance, family support and excellent GIST specialists keep me moving forward. I would advise anyone with this diagnosis to try to find the best doctor and research hospital in your area and follow the experts' advice while asking questions and trying to stay positive.

I learned about The Life Raft Group during the summer of 2007. Their motto at the time was "we're all in this boat together." Their monthly newsletters and emails provided reports and updates about current treatment and the results of advancements of GIST research, monitoring and treatment developments as well as patients' stories of their journey and successes. It was a "Life Raft" for me as I moved forward. The Life Raft Group has been a source of information that had not otherwise been readily available.



2007

In May 2024 I needed another surgery with the result showing that my tumor developed an Exon 13 mutation over time. I now take sunitinib malate (Sutent), the second line protein inhibitor, and it seems to be doing its job. Now dealing with different side-effects than from the imatinib.

Since 2007 I been provided advice, treatment and genuine concern from all my brilliant and skillful GIST physicians (specialists in the field): Drs. William Tap (Chief of the Sarcoma Medical Oncology Service), Ronald DeMatteo (formerly my surgeon at MSKCC and now Chair of the Department of Surgery at the Perelman School of Medicine at the University of Pennsylvania) and Jonathan Trent (Associate Director for for Clinical Research, Director of the Bone and Soft-Tissue Sarcoma Group,

and Professor of Medicine at the Sylvester Comprehensive Cancer Center at the University of Miami). Additionally, together with the physicians and staff at Sylvester Comprehensive Cancer Center hematological, gastroenterology departments, CTU units and the staff at MSKCC, University of Pennsylvania and Sylvester Comprehensive Cancer Center at the University of Miami. These men and women have worked diligently to provide excellent medical care, and ultimately my survival, during the last 19 years.

With a bit of luck and more treatment options I hope and plan to continue living for many more years to come.

## Patient of the Month - May

by Gonzalo Arroyo Ortega of Spain

### Gonzalo's GISTory

It was first diagnosed with GIST cancer in October of 2019. I had some abdominal pain, which was quite bearable and it came and went but I wanted to find out what was causing it. After a few misdiagnoses I went to see a urologist who asked me to take a TAC image (CAT scan) of the abdomen.

With that test came the diagnosis: a GIST tumor.

My first reaction was utter panic and fear. I had never heard of GIST, but the word tumor next to it made it terrifying all the same. I remember that evening asking my father who is a neurologist and he had never heard of such tumor. I also called a digestive tract doctor, and she had heard of it, but didn't know much about it.

My wife and I immediately got moving to find the right specialists to inform me of my situation and to help fight it.

I very quickly got an appointment with Dr. Emilio De Vicente, who is probably the leading surgeon of the digestive system and abdomen. He requested a whole array of tests and quickly calmed me by informing me that the GIST tumor has a high survival rate and he would remove it and I would never hear about it again.

He removed a 10 cm tumor in my duodenum, and a few days later the pathology result came in. It was the most aggressive type, and I would need to take imatinib for three years. That was my first time really being hit hard by the illness.



I began taking imatinib 400 mg / day under the supervision of Dr. Cesar Muñoz and had TAC tests (CAT scans) every three months. Everything went according to plan, and I was cancer free for those three years.

After that period had passed, I continued having TAC tests (CAT scans) every 3 months, and I was confident that I had left the disease behind me for good.

In December 2024 in one of those routine TAC tests (CAT scans), everything changed. They found three tumors in my liver.

I was in shock, but with the help of my wife, I got back up and started fighting again.

I changed my doctor since Dr. Muñoz had moved on to research duties and no longer had patients directly under his care. I found an excellent new doctor with a lot of experience in GIST tumors – Dr. Rosa Alvarez.

I am back on imatinib 400 mg/day for an indefinite period and since then I have had a successful ablation with microwaves of two of the three tumors.

The tumor remaining is not growing and it's responding satisfactorily to the imatinib treatment. I have TAC screenings (CAT scans) every three months.

My attitude is normally of optimism, but I can't help thinking that the good news could change to bad news any day, since I am aware of the high percentages of imatinib-resistant tumors, but I have also grown closer to God since my second diagnosis, and that together with my the support of my family it's what is keeping me strong.



## How I cope with GIST

I am coping well with GIST. Obviously, it was a real disappointment to find out that it had reappeared, but I am keeping strong and confident.

## My advice to fellow GISTers

My advice to fellow GISTers would be to make sure that you find an oncologist who has ample experience in treating GIST, and that if it is up to you to take imatinib as long as possible.

## Hobbies I enjoy

My main hobby is reading. Specifically, history, philosophy and religion. I have a strong faith in my Christian religion and since my new diagnosis I have found a lot of strength from it. Besides that, I like to spend all the possible time with my family.

## My #GISTLife Motto

I don't really have a motto or quote I live by, but I guess my way of seeing life would be, ***“Do the right thing and have faith.”***



## Long-Term GIST Survivors Share Advice

by Daniela Saunders, LRG Volunteer

The LRG hosted three long-term GIST survivors on a recent webinar and had an honest conversation around what to do after a GIST diagnosis, common mistakes to avoid, and what it's like to live with cancer long-term.

### The Diagnosis Stories of Long-Term GIST Survivors

For all three panelists, a diagnosis came abruptly.



Kay's tumor was discovered during an endoscopy related to another issue. "I did what everyone does when they're first diagnosed and googled GIST. The more I learned, the more afraid I became," she said. Without mentors or a support network, she was treated by doctors that were not GIST experts and received erroneous information. Eventually, she found The Life Raft Group and said, "I believe The Life Raft Group saved my life just through knowledge and connections with other GISTers."



John's diagnosis came in 1997, before GIST was recognized as its own disease. After having pain for six to 12 months, he had an endoscopy which found a tumor. He had surgery to remove it the same day. He also underwent months of chemotherapy that we now know is not recommended for GIST.



Martha was 57, healthy, and teaching fitness classes when emergency surgery revealed a large, small-bowel GIST. "I woke up to hear my name and cancer in the same sentence," she recalled. "It's the blow of a lifetime."

### The Most Important Advice for Newly Diagnosed Patients

All three panelists emphasized that new patients should see a GIST specialist as soon as possible.

Martha's local oncologist had limited experience treating GIST patients and was not aware of mutation testing, so she initiated it herself. When he was not interested in the results of the test, she trusted her instincts and referred herself to MD Anderson. "You think if you go to a specialist, the news is going to be worse...but actually, it's just the opposite because once you see a specialist, you know you've done everything you can," she said. "You can go on with your life."

John, who mentors other GIST patients, often sees the same pattern: “Most people like their physicians, so they trust them, as they should. But there are plenty of oncologists that don’t know much about GIST. The two keys to survival are specialists and biomarker testing.”

Kay echoed this: “Do not be afraid to hurt your oncologist’s feelings. You have cancer and they’re going to go home at night and it’s not going to affect their life. It is absolutely going to affect your life. So, don’t be afraid to hurt your oncologist’s feelings and get a second opinion. And any doctor worth their salt would encourage you to get a second opinion and a third opinion if that’s what you need.”

Find a GIST specialist in the LRG GIST Specialist Database: <https://liferaftgroup.org/gist-specialist-list-us/>

### **Living with GIST Long-Term**

Kay, John and Martha have been living with GIST for decades and shared their coping strategies in this webinar.

John maintains a “healthy sense of denial”: “There isn’t a day that goes by that I don’t think about it for one reason or another, but it doesn’t define me, and it doesn’t control me.”

Martha said “I think the best way to address that feeling of worrying about it all the time is to know you’ve done the best you can for yourself. You must eat healthy. You’ve got to exercise even though you don’t feel like it. You’ve got to get out with other people. That’s the only part of your longevity that you really have any control over.”

Kay has learned how to compartmentalize to handle scanxiety\*. “I really don’t get anxious when I get a scan. I’ve decided to wait until I see the results or I hear from my doctor. I have decided not to get excited until I have a fact. That’s how I handle it.”

To anyone newly diagnosed with GIST who may be reading this: the early days can feel overwhelming and frightening. But knowledge, expert care, and a supportive community can make an enormous difference. Take things one step at a time, one day at a time, ask questions, and know that you are not alone. There is an entire community of patients, doctors, and advocates walking this path with you.

\***Scanxiety** is the stress and uncertainty many people feel around medical scans and test results. It is that feeling of worry before a scan, while waiting for answers, or wondering what comes next.

### **The Power of Community**

Each panelist spoke about the profound impact of connecting with other GIST patients through The Life Raft Group.

John didn’t discover The Life Raft Group until 20 years into his journey with GIST, but once he did, it transformed his experience. “The Life Raft Group has enhanced my life beyond what I can talk about. It’s just been phenomenal for me.”

Kay recommended Life Fest, which will be held in Nashville this summer: “It’s a sacred space where you are safe to be with other people just like you. And there’s no “grocery-store talk”. You get to the real meat of the issue right away with people. There’s no pretense. There’s just a common bond that we all feel with each other.”

Martha said this about Life Fest: “Once all the layers are peeled back and we’re all human again, it’s just the greatest bunch of people in the world. It’s just the most important thing in the world to have peers.”

You can find more details about Life Fest registration & info: <https://bit.ly/LifeFest2026GIST> here.

Every GIST journey is different, but one thing is clear: learning from others matters. The experiences shared by long-term survivors remind us to ask questions, seek expert care, speak up for ourselves, and lean on support when we need it. If you are newly diagnosed or feeling uncertain, know that others have walked this path before you and you do not have to face GIST alone.

## Have a question for long-term GIST survivors?

Ask what is on your mind. Their experiences may help guide, reassure, or support someone else on the journey too.

Use this [link](#) to ask your questions.

This article is a summary of the actual webinar that took place last month. You can watch the recording [here](#).



## Other Resources for Patient Support:

[GIST Mentor Program](#)

[GIST Chat](#)

[Support Groups](#)

[Facebook Survivor Chat Group](#)

## LRG Athletes for GIST Take On The Miles!

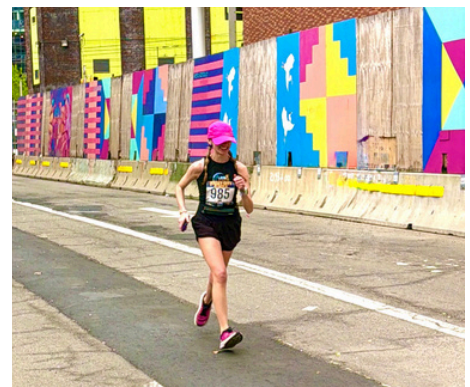
### LRG Athletes for GIST Hit Milestones!

by Egný Mendoza, Communications Associate

The LRG Athletes program brings together individuals who use personal fitness goals and endurance challenges to raise awareness and support for the GIST community. Every mile completed by an LRG Athlete represents strength, determination, and a shared commitment to helping patients and families impacted by GIST. This year, two members of the LRG community reached inspiring milestones through races that carried meaning far beyond the finish line. The LRG Athletes program brings together individuals who use personal fitness goals and endurance challenges to raise awareness and support for the GIST community. Every accomplishment completed by an LRG Athlete represents strength, determination, and a shared commitment to helping patients and families impacted by GIST. This year so far, two members of the LRG community reached inspiring milestones through races that carried meaning far beyond the finish line.

#### Toni Pauwels Runs Her Second Marathon as an LRG Athlete

LRG Staffer Toni Pauwels completed her second marathon as an LRG Athlete, making it an especially meaningful milestone. As a Data Management & Research Manager at The Life Raft Group, Toni works behind the scenes and directly with families affected by GIST, helping patients and caregivers find answers, access resources, and feel supported through some of the hardest moments of their lives. Her work goes far beyond administration, it is deeply personal, and it is one of the main reasons she is inspired to run for the GIST community.



For Toni, running has become more than a sport. It has become a way to turn purpose into action. She has shared that running helps her manage stress and stay grounded, while also giving her the opportunity to raise awareness for a rare cancer that many people have never heard of until it touches their lives. Each step on race day reflected the resilience she sees in the GIST community every day.



Completing 26.2 miles is never easy but doing it for a second time as an LRG Athlete shows her determination. She was not simply chasing a finish line, she was honoring the strength of the patients she speaks with, the caregivers she checks in on, and the community she serves with heart every single day.

Thank you, Toni, for turning your personal goal into something that inspires so many others. Your dedication on and off the course continues to make a difference. And thank you to everyone who donated and showed support for Toni's journey.

### Edoardo Leone Delivers an Inspiring Performance at IRONMAN 70.3 Chattanooga

LRG Athlete Edoardo Leone delivered an inspiring performance at the Race IRONMAN 70.3 Chattanooga, earning a P8 finish in just his third professional race. Competing on a challenging course marked by steep hills and intense heat, Edoardo described the race as an important milestone in his journey as a professional athlete and a reminder that hard work and sacrifice continue to pay off.

Beyond the finish line, this race carried a deeper meaning. Edoardo chose to dedicate his performance to supporting The Life Raft Group in honor of a friend living with GIST. Through the encouragement of his supporters and community, nearly \$2,000 was raised to help advance research and patient support efforts.

Thank you Edoardo for sharing your story and supporting the GIST community. Your dedication, both as an athlete and advocate, continues to inspire others and reflects the powerful impact that personal connections and community support can make. Thank you to all who supported his efforts!



You can be an LRG Athlete and let your journey fuel hope for others! Learn more [here](#).

See Toni's and Edo's full journey by viewing their kudoboard.

**Toni Pauwels - LRG Athlete for GIST**

Welcome to Toni's page! This is her place to share about her newest athletic challenge. Follow Toni on the way to her goal to raise funds for GIST research.

DONATE: <https://bit.ly/Toni-Marathon26>

Read more about LRG Athletes here:

Go to board

**Edoardo Leone - LRG Athlete for GIST**

Welcome to Edoardo's page! This is his place to share about his newest athletic challenge. Follow Edoardo on the way to his goal to raise funds for GIST research.

DONATE: <https://bit.ly/LRG-A-Edoardo>

Read more about LRG Athletes here:

Go to board

### Miami Precision Biannual Conference

by Toni Pauwels, Data Mgmt. & Research Manager



MIAMI, FLORIDA - I'm still thinking about my time at the Miami Precision Biannual Conference in Fort Lauderdale. It's one of those experiences that really stays with you.

From the moment I arrived, everything just felt aligned. The weather was beautiful- blue skies, sunny and warm, and it set the tone for the entire weekend. Even the commute there felt memorable. On the way to the hotel, I caught a glimpse of an outdoor concert featuring Ice Cube and Post Malone!

When I arrived at the conference location, I was welcomed right away, and it was clear how thoughtfully organized the conference was. Walking through the space, I saw booths from patient advocacy organizations and pharmaceutical companies that I am familiar with. It was incredibly powerful to see so many people in one place, all working towards improving the lives

of patients. One of the most meaningful conversations I had was from the co-founder of the KRAS Kickers. He shared how his wife started the organization and continues to lead it, and you can feel how personal that mission is to him. His message about the importance of patient self-advocacy really stayed with- that sometimes, getting the right care means asking questions, pushing for answers, and not being afraid to take an active role in your own treatment journey.

I also had the chance to connect with many survivors. One that stayed with me was a young patient who discovered a hereditary cancer mutation after a family diagnosis, which ultimately led to early detection of her own cancer. Now in remission, she continues close follow-up care with a multidisciplinary team due to her genetic risk. What stood out most was her openness about the emotional and mental challenges of her journey, not just the physical aspects, and how she has turned her experience into advocacy for early detection, genetic testing, and mental health.

A personal highlight for me was being part of the panel “Thriving Beyond Cancer Risk or Diagnosis — Practical Self-Care Strategies.” It was such an honor to be included in that conversation. When I was asked how education has shaped my self-care, especially in the rare cancer space, I shared that knowledge has been one of the most grounding and empowering tools. It doesn't take away the uncertainty, but it helps you navigate it. It allows patients to ask better questions, seek out the right specialists, and feel a sense of control in situations that often feel overwhelming.



When asked what advice I would give to someone newly diagnosed or at high risk, I said something I truly believe: you don't have to go through it alone, and you shouldn't. Finding your community, whether it's through patient groups, specialists, or others who understand your experience can make all the difference. And just as importantly, don't be afraid to use your voice. Your concerns, your questions, your instincts—they matter.

I also had the opportunity to meet Dr. Jonathan Trent, which was incredibly meaningful. He was warm, approachable, and clearly passionate about helping patients, especially in the rare cancer space. It's always reassuring to meet clinicians who truly see and care for the whole patient.

One of the most full-circle moments for me was meeting a Life Raft Group GIST patient at the conference. He shared that he came specifically to learn more about his condition. That moment really stuck with me because that's exactly what self-advocacy looks like. It was a powerful reminder of why access to education and community is so important.

Overall, I left the conference feeling grateful, inspired, and proud. Grateful to have been there, inspired by the people and stories I encountered, and proud to represent The Life Raft Group. Being able to bring the GIST patient voice into that space meant a lot to me.

Experiences like this remind me why this work matters so much. When patients, advocates, and clinicians come together, there's a real sense of purpose!

## SPAGN Conference 2026

by Tara Ruggiero, Program Coordinator

STOCKHOLM, SWEDEN - Day one of the SPAGN Conference 2026 centered around the message: patients need to be part of the conversation when it comes to improving sarcoma care and research. There were a lot of discussions about making support more accessible, improving collaboration in research, and how patient-reported outcomes are helping shape treatment decisions and policies.



It was also inspiring to hear about the work patient organizations are doing through awareness campaigns, registries, support programs, and advocacy efforts. One thing that kept coming up throughout the day was the importance of treating the whole patient, not just the disease, but the emotional and practical challenges that come with it too. Overall, the day reinforced how much progress depends on patients, researchers, doctors, and advocates working together.

Day two focused a lot on how patient organizations are becoming true partners in research and advocacy, not just participants. It showed how SPAGN has grown into such a strong international network involved in research, policy, clinical trials, and awareness efforts around the world.



A theme that really stood out was that lived experience matters and should be recognized as expertise. Speakers talked about how involving patients in meaningful ways improves research, study design, and ultimately patient care. There was also a strong focus on the need for earlier diagnosis, better access to specialized sarcoma centers, and more global collaboration. The overall feeling from the day was hopeful. By building connections and learning from each other, real progress is happening.

Day three focused on collaboration, care, and what happens after treatment ends. One discussion that impressed me was about adolescents and young adults (AYA) and the long-term emotional impact cancer can have. For many patients, the emotional processing doesn't fully happen until after treatment is over.

The conversations throughout the day also reinforced the importance of individualized care, second opinions, multidisciplinary teams, and making sure patients truly understand their treatment options. One of the biggest takeaways from the conference was that improving sarcoma care is about much more than better treatments, it's about supporting patients through every part of the journey, before, during, and long after treatment.



BOSTON MASSACHUSETTS - Executive Director Sara Rothschild traveled to Boston to participate in Deciphera's Patient Advocacy Summit with other advocates on the importance of community engagement and priorities setting.

## Featured Events:



**WEBINAR**

**Expert Nutrition & Exercise Advice for Sarcoma Patients**

Monday, June 1<sup>st</sup> - 12 PM ET

**Dr. Loren Yavelberg**  
University of Miami

**Dr. Harleen Kaur**  
University of Miami

**The Life Raft GROUP**

[REGISTER](#)



## Life Fest 2026

July 10-12th  
Lowes Vanderbilt Hotel  
Nashville, Tennessee

Join us at this weekend-long educational event for patients & caregivers.

## Life Fest Nashville is Calling You!

by Rebecca Pauley, Program Director

So you haven't decided yet if you should book a flight to Tennessee to come to Life Fest? You keep pulling up the website...and then closing it again. How many days off would I take? I don't know anyone going. Who's going to watch the kids?

Those are real questions, and really, they're the same ones almost everyone asks before they decide to come.

No one shows up to Life Fest for the first time knowing a room full of people. But it doesn't stay that way for long. Within the first few hours, you start meeting people who just get it, people who understand the language, the decisions, the uncertainty, and the small wins that feel huge. By the end of the weekend, it doesn't feel like you came alone at all.

And yes, taking time off and figuring out logistics isn't easy. Life doesn't pause just because you need space to learn, connect, or recharge. But that's exactly why Life Fest matters. It's a rare chance to step out of the day-to-day and focus on YOU! This is a time to focus on your questions, your understanding, and your next steps.



Some photos from past Life Fest conferences. See highlight reel of Life Fest 2024 San José to the right.

What you get in return goes far beyond a typical event. You'll hear directly from experts, but in a way that actually feels accessible. You can ask the questions you've been Googling at 2 a.m. You'll learn about treatment options, research, and clinical trials, but more importantly, you'll hear how those things play out in real life from people who've lived it.

Then there are the moments you can't plan for: the conversations in the hallway, the shared stories over coffee, the feeling of relief when someone says something you've been thinking but haven't been able to put into words. Those are the moments people talk about long after Life Fest ends.

There's also something powerful about being surrounded by a community that's not just coping, but actively pushing things forward. Patients, caregivers, researchers, advocates, it's all happening in one place. You start to see where you fit into that bigger picture, and it can change how you think about what's possible.

So yes, it takes effort to get there. It might mean arranging childcare, using PTO, or stepping outside your comfort zone. But most people who come will tell you the same thing: IT WAS WORTH IT! Because Life Fest isn't just another event you attend. It's one you feel, and one you carry with you long after you've gone home.



**REGISTER TODAY**

# Adventure in Nashville – See the Sights & Sounds

by Brianna Enciso, Development Manager

Life Fest is more than a conference. It is a chance to reconnect with people who truly understand the rare disease journey, share experiences, learn from experts, and spend meaningful time with a community that feels like family.

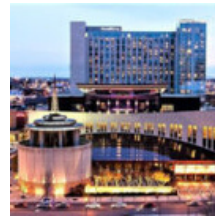
We are looking forward to experiencing the heart of Nashville, a city known for music, energy, history, incredible food, and unforgettable experiences. After a long day of learning about GIST and conversations with fellow patients and caregivers, don't forget to carve out time to explore everything "Music City" has to offer.

Whether you are traveling with family, meeting online friends in person for the first time, or simply looking forward to a few days surrounded by people who "get it," Life Fest 2026 is designed to be both educational and uplifting. [Register today](#). – Don't miss out!



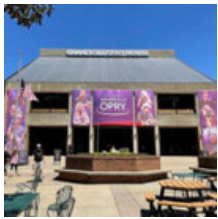
## 1. Explore Broadway!

Take a walk down Nashville's most iconic strip filled with live music, honky-tonk bars, restaurants, and energy  
<https://www.visitmusiccity.com/things-to-do-in-nashville/music-entertainment/guide-to-honky-tonk-highway>



## 2. Visit the Country Music Hall of Fame and Museum!

Dive into the rich history of country music through interactive exhibits.  
<https://www.countrymusichalloffame.org/>



## 3. Experience the Grand Ole Opry!

Catch a live show at one of the most famous stages in music history and see today's stars and legends perform.  
<https://www.opry.com/>



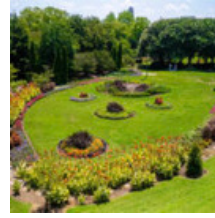
## 4. Tour the Ryman Auditorium!

Known as the "Mother Church of Country Music," this historic venue offers tours and incredible acoustics.  
<https://www.ryman.com/>



## 5. Step into history at The Parthenon!

Located in Centennial Park, this full-scale replica of the original in Greece is a must-see and great for photos.  
<https://www.nashville.gov/departments/parks/parthenon>



## 6. Relax at Centennial Park!

A beautiful green space perfect for a stroll, picnic, or just enjoying the outdoors.  
<https://www.nashville.gov/departments/parks/parks/centennial-park>



## 7. Walk through The Gulch!

A trendy neighborhood known for murals, boutique shopping, and popular dining spots. Don't miss the famous "What Lifts You" wings mural!  
<https://www.alittlelocalflavor.com/blog-posts/best-ways-to-see-nashville-murals>



## 8. Discover the Johnny Cash Museum!

Explore the life and legacy of Johnny Cash through one of the most comprehensive collections of his work.  
<https://www.johnnycashmuseum.com/>



## 9. Enjoy live music at Bluebird Cafe!

An intimate venue where songwriters perform and share the stories behind their music.  
<https://bluebirdcafe.com/>



## 10. Take in the views at Cumberland River Greenway!

Perfect for walking or biking while enjoying scenic river views and the Nashville skyline.  
<https://www.trolleytours.com/nashville/scenic-views>



For more ideas, visit:

<https://www.visitmusiccity.com/>



## Walk for Hope at Life Fest 2026

7:00 AM July 12th

Walk with us to raise funds  
and awareness!

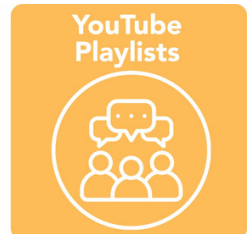
**SIGN UP TO WALK**

### Recordings:

Recordings from the **GIST Summit / GDOL Texas** at MD Anderson Cancer Center are now available.

**WATCH GDOL BOSTON**

### SUPPORT & CONNECTION



**The Life Raft Group**  
973-837-9092  
liferaft@liferaftgroup.org  
[www.liferaftgroup.org](http://www.liferaftgroup.org)

Follow us on social media:

