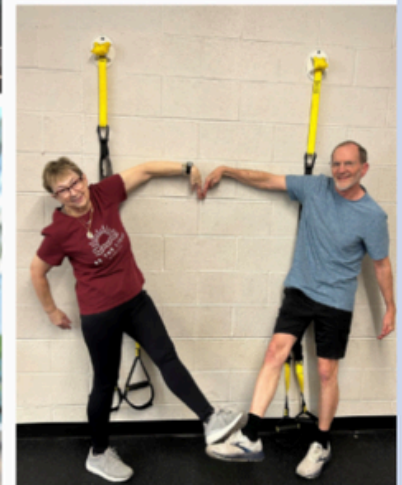


MARCH 2026 NEWSLETTER



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.

In this issue of our newsletter, you'll find our latest GIST study, a piece on expanded access, patient stories, webinar highlights, and recaps from recent events. You'll also find ways to get involved, from LRG Athletes to upcoming opportunities to connect with the GIST community.

New Paper on Adjuvant Imatinib in Exon 9

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

Adjuvant Imatinib or Observation in Patients with Gastrointestinal Stromal Tumors with KIT Exon 9 Mutations¹

Published on February 26, 2026, in JAMA Oncology, this international study represents a major collaboration between The Life Raft Group and thirty-five leading cancer centers across the U.S., Europe, and Japan to better understand treatment for gastrointestinal stromal tumors (GIST) with KIT exon 9 mutations. Researchers analyzed outcomes from 367 patients with localized disease at diagnosis who underwent surgery to remove their tumors and examined whether imatinib taken after surgery (adjuvant therapy) improves survival.

The study found that patients who received adjuvant imatinib experienced a significantly longer time before recurrence (recurrence-free survival) and improved overall survival compared with observation alone, particularly among those classified as high risk by modified NIH (mNIH) criteria. Among 257 patients with mNIH high-risk disease receiving imatinib, no significant difference in outcomes was observed between 400 mg/day and 800 mg/day dosing.

These results provide the strongest evidence to date supporting adjuvant imatinib for patients with high-risk KIT exon 9–mutated GIST and clarify that higher dosing may not confer additional benefit in the postoperative setting.

¹Napolitano A, Joensuu H, Rothschild S, et al. Adjuvant Imatinib or Observation in Patients With Gastrointestinal Stromal Tumors With KIT Exon 9 Mutations. *JAMA Oncol*. Published online February 26, 2026. doi:10.1001/jamaoncol.2026.0007

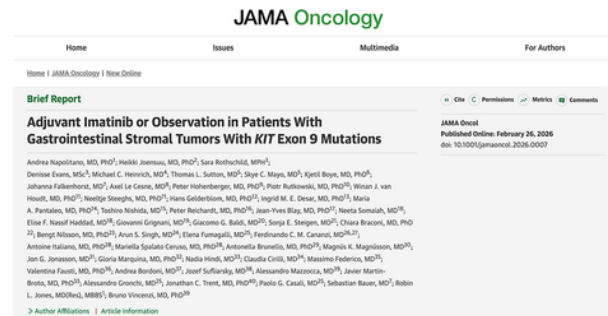
From **Denisse Evans**, Senior Director of Data Management & Research

The Life Raft Group is excited to share our latest study on adjuvant imatinib in KIT exon 9–mutant GISTs, a biologically distinct subset with reduced sensitivity to standard-dose therapy in advanced disease. In our multinational cohort (35 centers, Europe, US, Japan), we applied time-dependent and causal inference models to assess recurrence-free and overall survival.

- Adjuvant imatinib delays recurrence (HR 0.19 early effect)
- Improves overall survival (HR 0.37)
- Benefit is consistent in mNIH high-risk patients
- No clear difference between 400 mg vs 800 mg daily dosing in high-risk patients

These results reinforce adjuvant imatinib for high-risk KIT exon 9 GIST and highlight the need for prospective studies on optimal dose and duration. LRG GIST Patient Registry data was used as part of this study. I am grateful to the patients and caregivers who contributed their experiences; their participation creates a lasting legacy of knowledge that advances research in rare GIST subtypes.

Special recognition & gratitude to Dr. Andrea Napolitano for his leadership in advancing care for this rare GIST subgroup.



[READ FULL ARTICLE](#)

What does an Expanded Access Program mean for GIST patients?

by Simran Singh, *Data Mgmt. & Research Manager*

Pharmaceutical companies may create an expanded access program (sometimes called compassionate use) when a clinical trial is no longer enrolling but the medicine still shows promise. This program gives patients with serious or life-threatening illness another way to try the investigational treatment if they cannot join the trial and have few or no other options. It allows doctors to request the drug for their patients while the company continues to study it and work toward possible approval. Expanded access can also help researchers learn more about the drug's safety in real-world use, while offering hope to patients who need more choices.



The quick FAQs:

What is Expanded Access?

Expanded Access Programs (EAP), also known as compassionate use, allow patients to receive investigational clinical trial drugs outside of clinical trials settings. This option may be available for patients who have exhausted all approved treatment alternatives.

Am I eligible?

Each EAP has its own eligibility criteria. In general, if you do not have other approved treatment options, an expanded access program may be an option for you.

How does it work?

EAPs are administered by pharmaceutical companies. Approval is granted at the company's discretion based on program requirements. Your doctor will submit a request on your behalf to the program to see if you may qualify.

Are there limitations?

Participation in some expanded access programs may be limited, as some hospitals may face restrictions on the number of clinical trial related programs they can conduct.

If you are considering starting a new treatment, reach out to us. We may be able to help you understand what options or programs could be available to you.

Interested in learning more?

If you are interested in current expanded access programs, please contact:

ssingh@liferaftgroup.org or **(973)-980-2945**

Histotripsy: What Patients Need to Know

by Daniela Saunders, *LRG Volunteer*

The Life Raft Group hosted a webinar bringing together top experts in a new procedure called histotripsy. The objective of the discussion was to provide clear, realistic, and compassionate answers about what histotripsy can and cannot do. This webinar was created in direct response to overwhelming interest and thoughtful questions from our community.

Moderator: Dr. Elizabeth Lilley of Brigham and Women's Hospital

Panelists:

- Dr. Jiping Wang (co-lead, Mass General Brigham Histotripsy Program)
- Dr. Chandrajit Raut (Brigham and Women's Hospital/Harvard Medical School)
- Dr. Hop Tran Cao (MD Anderson Cancer Center)
- Dr. Christina Angeles (University of Michigan)
- Dr. Alicia Gingrich (University of Nevada/Renown Health System)
- Dr. Suzanne George (Dana-Farber Cancer Institute)

[VIEW WEBINAR](#)

Summary

What Is Histotripsy?

Histotripsy is a noninvasive procedure that uses a new form of focused ultrasound energy to destroy tumor tissue, without damaging surrounding tissue. The ultrasound energy is delivered via a software-guided machine which destroys the tumor at the cellular level, often in just one session. The cellular debris from the destroyed tumor is then absorbed by the body.

Right now, histotripsy is approved by the FDA to treat cancers of the liver only. Liver tumors are the logical first use of histotripsy because the liver is a large uniform organ which has excellent regenerative qualities and can be easily accessed with the histotripsy machine. Doctors do not recommend partial treatment of a tumor because leftover cancer cells may continue to grow. Initial clinical study showed high success rate after 1 year and low complication rate. Long term outcomes are still being studied.

What are the requirements when histotripsy is used to treat liver cancer?

To be eligible for histotripsy, liver lesions must be smaller than 3 centimeters, visible on an ultrasound, and not near critical structures like the bowels. Since patients undergoing histotripsy must be completely still, general anesthesia and intubation are required. If a patient is not a good candidate for general anesthesia due to underlying heart or lung problems, they are also not a safe candidate for histotripsy.

Can histotripsy be used to treat GIST?

GIST tumors may occur anywhere in the digestive tract, most commonly the stomach (40-70%) or the small intestine (20-40%). At this time, those body areas are not FDA approved to be treated using histotripsy. But if GIST spreads to the liver, doctors might consider histotripsy. The panelists emphasized that this decision should be made after a multidisciplinary discussion including both medical oncology and surgical oncology clinicians about the full range of treatment options, based on the location of the lesion, the size of the lesion, and what other drugs or clinical trials could be considered options. Histotripsy is not recommended for localized primary tumors that can be safely removed using surgery.

Can histotripsy be used to treat other sarcomas?

For sarcoma and other cancers, research is in early stages. There are many different subtypes of sarcoma, and sarcomas can behave in widely different ways so doctors have been testing histotripsy on sarcoma tissue that has been removed surgically to see what happens to the different subtypes. In another preclinical research study, doctors have started animal testing. In addition, doctors are working on developing a safe clinical trial protocol.

What is the abscopal effect and is there data that histotripsy induces it?

The abscopal effect is a hypothesis that a treatment on one tumor could somehow activate your body's immune system to go after cancer elsewhere in the body. There is some thought that there could be an abscopal effect for histotripsy because you're not destroying the tumor with heat so you're not modifying the antigen. None of the panelists have seen this effect among their patients and cautioned people to be skeptical.

How can patients stay informed about the progress of histotripsy research and the results?

Patient-facing webinars and other forums where doctors speak about their research are good ways to keep up to date. The general consensus is that it will be at least one year before there is a clinical trial. Doctors learn a lot from outcomes data from current patients so please consider participating if your doctor asks you to take part in a registry trial.

Thank you to our moderator and panelists for a great, well-rounded discussion, and thank you to our patient community for joining us!

In case you missed it:

Patient of the Month - March

by Barney Mulvihill of California

Barney's GISTory

I am a 44-year-old father of two wonderful kids, Harry and Alannah. My wife Emma is a hairdresser, and I work in the medical device industry developing prosthetic heart valves. I have worked in that field for about 15 years.

Before my diagnosis I lived a very active lifestyle. I regularly ran 10km, played soccer, and went to the gym. Emma and I both grew up in Ireland. In 2016 my work offered our family the opportunity to move to Southern California. It was a big change from our life in Galway on the west coast of Ireland, but we saw it as an amazing adventure for our young family. The original plan was to stay three years. That was ten years ago. We built a wonderful life in Southern California and were enjoying a very normal, family-focused life. Then everything changed.

May 7th, 2025, is a date I will never forget. I had to leave work early because I was experiencing severe abdominal pain and went to the emergency room in Mission Viejo. I assumed it was something minor — maybe indigestion or gallstones. Instead, after several scans, a doctor came into my room late that night and told me something I never expected to hear. There were large tumors in my stomach and liver and they appeared cancerous. Cancer had never affected our immediate family before, so the news was completely shocking. At first, I honestly thought the doctor must be mistaken. I simply couldn't process what I was hearing.

In that moment I was told the situation looked very serious. That night I stayed awake, alone in the hospital doing two things: thinking about how I would tell Emma and my family and writing letters to my wife and children.



The following morning, I underwent a liver biopsy. Later that day I was lying in the hospital room trying to distract myself by watching television. By coincidence, it was the day the new Pope was elected, and I watched the white smoke appear live on TV. The hospital also sent a priest to visit me. I congratulated him on his new boss, and he said some prayers with me. I'm not particularly religious, but it's amazing the small moments of kindness you remember when life suddenly turns upside down. One of the hardest things I had to do was break the news to my wife, Emma. We cried for a long time before leaving the hospital in complete shock and uncertainty for the future. We told our close neighbors and friends, Katie and Ryan, and the tears started all over again.



About two weeks later the biopsy results came back and I heard a word I had never heard before: GIST — gastrointestinal stromal tumor – which is a type of sarcoma cancer. Perhaps it's the engineer in me, but I immediately began researching everything I could about the disease and the best specialists who treat it. The ER doctor who cared for me that first night showed incredible compassion and kindness in the following days by staying in touch, something I will never forget. During my research, I also discovered the incredible resources provided by The Life Raft Group. I spent days and nights watching videos, reading patient stories, studying research papers and learning everything I could about GIST. That knowledge helped me begin to understand the path ahead.

Through my research I was fortunate to connect with Dr. Jason Sicklick at UC San Diego, one of the leading GIST specialists in the United States. I also met his colleague Dr. Paul Fanta, also a leading oncologist specializing in GIST. From the moment I met them I felt I was in the right hands. Initially I was treated with imatinib (Gleevec), but we soon learned that my tumor carried the SDHA variant of GIST, which often behaves differently and may not respond well to standard treatments.

We also tried temozolomide (TMZ) but unfortunately scans showed continued tumor growth in my liver. Because controlling the liver metastases became the immediate priority, Dr. Fanta recommended Y90 SIRT (radioembolization) — a targeted radiation treatment delivered directly to the liver. I underwent two Y90 procedures, treating the left side of my liver first and then the right side.

Today my journey continues. My energy levels are not what they once were and fatigue is something I manage daily, but pain is currently minimal and we are hopeful that the treatments — including radiation and immunotherapy — are helping control the disease. The past nine months have been a challenging journey, and I know there may be more twists and turns ahead. But I also know I am not facing it alone.

Coping with a GIST Diagnosis

For me, coping comes down to staying informed, staying connected, and focusing on what matters most. The GIST community has been incredible. Through The Life Raft Group I connected with other patients and joined support groups, including a WhatsApp group for people living with SDH-deficient GIST. I try to stay informed about my condition and actively engage in my care. Understanding my scans, treatments, and options helps me feel more in control of the situation. Speaking with people who understand the same treatments, symptoms, and side effects has been incredibly helpful. I've also been deeply humbled by the strength and resilience of so many fellow GIST patients.

I also focus on continuing to live my life as normally as possible — working, planning, and thinking about the future all help to keep me distracted. Cancer may be part of my story, but it doesn't define my entire life. Of course, my greatest source of strength is my family. Spending time with my wife and children reminds me every day why I keep fighting.



Talking With Our Kids

One of the hardest parts of this journey has been explaining my illness to Harry and Alannah.

Children understand more than we sometimes realize, and we try to be honest with them while also reassuring them that I am doing everything possible to get better. They have shown incredible love, empathy, and resilience throughout this experience. Harry and Alannah are still young, but I hope that one day they will look back on this chapter of our lives and see not just the challenges, but the strength and love that carried us through it.

My message to them is simple: be curious, be brave, and always take on life's adventures — even when the path ahead is uncertain. Their hugs, their laughter, and even the normal everyday chaos of family life have become some of the greatest sources of strength and motivation for me.

His Advice for Fellow GISTers

My advice to anyone newly diagnosed is simple: Find a GIST specialist and connect with the community. GIST is a rare and complex cancer, and doctors who specialize in it truly understand the nuances of treatment options. Also, don't be afraid to ask questions. Understanding your disease and treatment options can help reduce fear and empower you to make the best decisions for your care. Finally, I also strongly recommend connecting with patient groups like those organized by The Life Raft Group. Speaking with other patients who understand the journey can make an enormous difference.

Hobbies He Enjoys

Outside of work and medical appointments, I enjoy spending time with my family, traveling, reading, and working on home improvement projects. I've always enjoyed building and improving things, and that mindset has helped me stay positive throughout this journey. Most importantly, I treasure time outdoors and being active with my kids.

GISTLife Motto

A cancer diagnosis brings uncertainty, but it also brings brilliant clarity about what matters most.

One idea that guides me through this journey is:

“Focus your energy on what you can control and let go of what you cannot.”

And another reminder I carry with me:

“Hope is stronger than fear.”

My journey with GIST is still unfolding. There will likely be more challenges ahead, but I move forward with gratitude for the incredible doctors treating me, the support of the GIST community, and most of all the love of my family.

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.

LRG on the Road: Representing the GIST Patient Voice in Texas

by Simran Singh, *Data Mgmt. & Research Manager*

Most days I spend my time behind a computer sending emails, curating data, or speaking with patients on the phone. Today was different. I was fortunate to be able to travel to Dallas, Texas to present on behalf of The Life Raft Group at the GSK StrateGIST3 Investigator meeting.

I spent my morning reviewing my presentation and waiting at the airport after several delays. While sitting at my gate, I struck up a conversation with an elderly couple sitting next to me. We began talking about what I do at The Life Raft Group and my role as a patient advocate. I felt an immense sense of pride sharing the work we do. The husband was intrigued and started asking questions about my background and even had a GI question. He shared his concerns, and I encouraged him to get a second opinion. The work of a patient advocate truly never stops :).

The following day, the meeting began, and I learned more about the research, clinical trial process, and eligibility criteria for StrateGIST3. During my presentation, I discussed the mission of the LRG, my role as a patient advocate, and described the patient journey.



In my role at the LRG, I welcome every new member who joins, and I support GIST patients as they learn about navigating resources, patient advocacy, and clinical trial awareness. Our team has a direct connection to the patient experience, and the many challenges people face daily. Healthcare providers are essential and having a doctor that is well-versed in GIST and up-to-date on the latest research is vital to the most effective care for your GIST. However, physicians cannot be everything for every patient and that is where we help fill in the gaps.

A patient's journey is never a straight line from initial symptoms to diagnosis to no evidence of disease (NED, which means – disease free). I felt it was important to highlight the many obstacles a patient may face along the way that is often overlooked by their healthcare teams. Such as misdiagnosis/delayed diagnosis, finding a specialist, insurance obstacles, educational resources (misinformation is unfortunately abundant), access to medication, cultural barriers, side effect management, understanding clinical trials, and the need for emotional and community support. Every patient's journey is different, and it is not as linear than it may seem.

The investigators were clinical trial investigators (medical oncologists and clinical trial coordinators) in North American, including USA, Canada, and Brazil. After my presentation, several investigators approached me to learn more about LRG. Fortunately, many were already familiar with LRG and listed as specialists on our website. I was able to make new meaningful connections and also connect people at the meeting with various resources to better support their patients.

GIST Summit / GIST Day of Learning 2026

by Brian Morello, *Director of Development*

The GIST Summit 2026, held on Saturday, March 21, at the MD Anderson Cancer Center in Houston, TX was a highly successful collaborative event that brought together approximately 125 patients, caregivers, medical professionals, and subject matter experts from across the country.

Hosted in partnership with The Life Raft Group and GIST Support International, the day focused on bridging the gap between clinical research and patient care, providing both elemental and the more complex nuances of GIST. Dr. Neeta Somaiah, The Life Raft Group's 2026 Clinician of the Year, did a masterful job in leading the Summit with not only her knowledge, but by engaging with some of the best medical experts in the country. Doctors Jonathan Trent, Michael Heinrich, Ping Chi, Heather Lyu and others impressed everyone with their expertise, forward thinking and compassion.



Topics discussed were GIST 101, the treatment of GIST, surgical approaches, drug development, and the next wave of therapies and trials. After breaking for lunch, the group came back together for a conversation with a trial patient and caregiver. The day concluded with a spirited Q&A – 'Ask the experts' panel and interactive roundtable discussions tailored to both the patient and caregiver.

It was a day that provided new promise and hope, and special connections for the GIST community.

We are excited to partner again with GSI in Houston next year to bring an even more robust and impactful experience for all.

Recordings of sessions will be available in the next few weeks.

To see more photos of the event:

<https://lifteraftgroup.kudoboard.com/boards/Js6Ok4Lv/GISTSummit2026>

Featured Events:

You can view registration details and agenda on the registration link.

Life Fest 2026

July 10-12th
Lowes Vanderbilt Hotel
Nashville, Tennessee

Register Today!



Nashville is your destination to **#FindYourCommunity** in 2026. Life Fest only happens every two years and is a weekend-long event for patients & caregivers.

Whether you are newly diagnosed or have been living with GIST for a long time, these expert educational sessions will bring you up-to-date on all things GIST. Learn more about current treatments, clinical trials, surgery, integrative oncology and more for GIST. SDH-deficient GIST patients can experience a specialized track for their unique subtype. Hear from and socialize with other patients and caregivers just like you.

Don't miss our next webinar focusing on **long-term survivors** & listen to our expert panel talk about **histotripsy** for sarcoma.

WEBINAR

What We Wish We'd Known Advice from Long-Term GIST Survivors

Monday, April 13 - 12 PM ET



Dr. John Abrams Piga Fernández Martha Smart Kay Stolzer

 The Life Raft
GROUP

[REGISTER](#)

WEBINAR

Histotripsy Demystified: Truths and Misconceptions Explained

RECORDING AVAILABLE

MODERATOR:
Dr. Elizabeth Lilley
Brigham and Women's
Hospital/Harvard
Medical School



Dr. Christina Angeles
University of Michigan

Dr. Suzanne George
Dana-Farber Cancer
Institute/Harvard
Medical School

Dr. Alicia Gingrich
University of Nevada
Renown Health

Dr. Chandrajit Raut
Brigham and Women's
Hospital/Harvard
Medical School

Dr. Hop S. Tran Cao
The University of Texas
MD Anderson
Cancer Center

Dr. Jiping Wang
Brigham and Women's
Hospital/Harvard
Medical School

[WATCH NOW](#)

Recordings from the **GIST Day of Learning Boston** at the Dana-Farber Cancer Institute are now available.

[WATCH GDOL BOSTON](#)

LRG ATHLETES WANTED! YOU CAN STILL BECOME AN LRG ATHLETE FOR 2026.



This year is starting with a bang! Toni P is running a marathon in Jersey City, NJ on April 19th for the LRG - see the details of her journey and support her with encouragement & a donation, if possible.

[SEE TONI'S JOURNEY](#)

If you, a friend or loved one, are planning on being in one of the Cleveland Marathon events, please consider being one of our LRG Athletes and make that run have more impact - a personal win for you and a win for #GISTresearch!

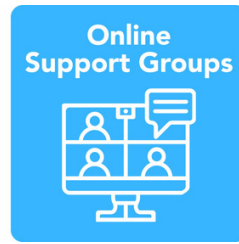
[REGISTER FOR CLEVELAND MARATHON WEEKEND](#)

LRG Athletes compete in many types of events whether they are personal goals or major competitions; pickleball to marathons. Use your passion to support the GIST community.

*Become an LRG Athlete this year!
Have fun & support our community!*

[BE AN LRG ATHLETE!](#)

SUPPORT & CONNECTION



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