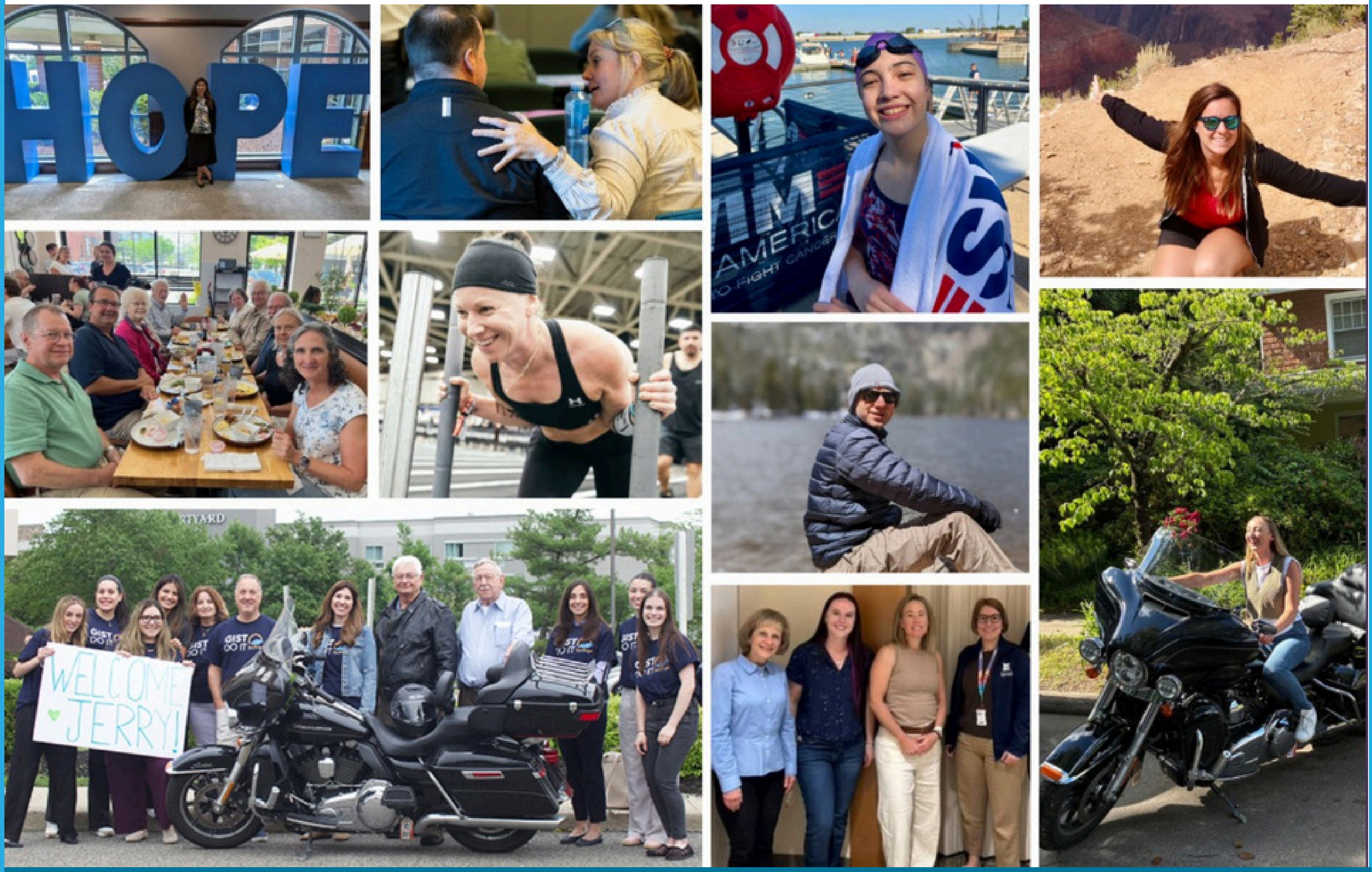
The Life Raft GROUP

JANUARY 2026 NEWSLETTER



Navigating Rare Together

Empowering Patients Living with GIST

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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 newsletter aims to be your guide to all things GIST and LRG. Our latest articles include a focus on health equity, sarcoma in the global arena, an overview of 2025, and a snapshot of what's coming in 2026.

Featured Articles:

Bridging the Gap

by Rebecca Pauley, *Program Director & Health Equity Council Facilitator*

For people living with gastrointestinal stromal tumor (GIST), a rare type of cancer, getting the best care is not always easy. Medical care is often shaped by more than just the disease itself. A person's age, race, language, income, insurance, and where they live can all affect how quickly they are diagnosed and how well they are treated. These differences can lead to delays, inability to access care, wrong treatments, and harm that could have been avoided.

The Specialist Gap

Rare cancers such as GIST necessitate a specialist to make educated care decisions. However, many people diagnosed with GIST never see a GIST specialist. Some community oncologists believe they can manage GIST on their own. But GIST is complex, and treatment guidelines change often. Specialists have deeper experience with this rare cancer.

Oftentimes, patients are even unaware they should be advocating for this specialized care due to lack of education at initial diagnosis. Even when doctors are willing to consult a specialist, referrals are often delayed or never made. This happens more often for older adults, patients of color, and people with fewer financial resources.

Insurance rules can make this problem worse. Even when a GIST expert is nearby, insurance may limit patients to smaller, in-network hospitals. Patients with rare diseases, like GIST, are then forced to fight for coverage and explain why they need specialized care, simply because their cancer is uncommon.

Missing Biomarker Testing

Many GIST patients also miss out on important biomarker testing. Biomarker testing helps oncologists understand the exact type of GIST a patient has and which treatments are most likely to work.

Without this testing, patients may be given treatments that are not the best choice for their mutation. This problem is more common outside large medical centers. It also affects patients with language barriers or limited health knowledge, who may not know these tests exist or feel comfortable asking for them.

The Cost of Not Being Told

Most general oncologists will see only one or two GIST cases in their entire careers. As a result, they often do not invest the time needed to fully understand the nuances of diagnosing and treating this rare cancer, particularly when they are managing far larger numbers of patients with more common malignancies. Many are unaware of how critical GIST specialty care is and therefore do not routinely refer patients to experienced centers or specialists.

When patients are not given this information, pursuing a second opinion, traveling to a specialized hospital, or appealing insurance decisions can feel unnecessary, intimidating, or overwhelming. Many patients reasonably assume that all oncologists treat cancer in the same way, without realizing that outcomes for rare cancers like GIST can vary significantly based on specialist expertise.

This gap in communication disproportionately affects individuals who already face barriers within the healthcare system, including older adults, people with limited financial resources, non-English speakers, and patients who feel unheard or overlooked. Without clear guidance on the importance of specialty care, patients are unable to make fully informed decisions about their treatment.

Patients with strong support systems, medical knowledge, or advocacy assistance are more likely to find specialty care on their own. Others, however, may never realize that better, more appropriate treatment options exist.

Education as a Tool for Fairness

The Life Raft Group's Health Equity Council (HEC) is working to reduce these gaps in GIST care. The HEC is building stronger connections between GIST specialists and community cancer centers, especially in rural areas of the Southeast United States.

Many oncologists in rural settings see very few GIST patients. They may not realize how much specialist care, biomarker testing, and updated treatment guidelines can change outcomes. The HEC helps address this through education, direct outreach, and practical tools that make referrals and consultations easier.

A key part of this work is helping oncologists clearly explain to patients why GIST specialty care matters. When doctors understand and communicate the life-saving value of specialist care early, patients are better able to decide whether travel, insurance appeals, or second opinions are worth the effort.

Through education, partnerships, and tools like virtual consultations, the LRG Health Equity Council is helping build a system where patients do not have to fight alone for expert care. This approach helps ensure that every person with GIST, no matter where they live, has access to the knowledge and expertise they need.

Call to Action

Better GIST care should not depend on where someone lives, what insurance they have, or how much they know about the healthcare system. Every GIST patient deserves access to the right testing, the right information, and the right specialists early in their care.

Patients and caregivers can take action by asking their doctors about biomarker testing and whether a GIST specialist should be part of their care team. Community oncologists can help by learning when to refer patients and by connecting with GIST experts when questions arise.

Supporters, healthcare providers, and policymakers can help by backing education efforts and programs that close gaps in care, especially in rural and underserved communities. By supporting The Life Raft Group and the LRG Health Equity Council, you help build a system where no GIST patient is left behind simply because of bias, distance, or lack of information.

Together, we can make expert GIST care the standard, not the exception.

To learn more about the LRG Health Equity Council, or to volunteer on the Council please email Rebecca Pauley at: rpauley@liferaftgroup.org

Sarcoma – The Cancer No One Talks About

by Rashi Kapoor, *President and Cofounder of the Sachin Sarcoma Society*

There are more than 100 types of cancer in the world. People are aware of and openly talk about cancers like breast cancer, blood cancer, and lung cancer. However, very few people talk about sarcoma, because it is an extremely rare cancer. Most people start hearing about sarcoma or searching for information only after they or their loved one is diagnosed.

I know this reality personally.

I am a two-time cancer survivor. I was diagnosed with synovial sarcoma in 2016, completed my treatment in 2017, and later underwent amputation in 2023. Living through sarcoma has not only shaped my life but has also given me a deep understanding of the struggles sarcoma patients face—physically, emotionally, socially, and financially.

My Journey and the Birth of Sachin Sarcoma Society

After completing my sarcoma treatment in 2017, I felt a strong need to give back to society. With the support of Dr. Sameer Rastogi, Additional Professor at AIIMS, New Delhi, I formed a sarcoma support group that later became Sachin Sarcoma Society (SSS) in 2018.

SSS was formed with a clear mission to spread awareness about sarcoma, build companionship among affected families, and remove the fear associated with this rare cancer. Over the years, we have been able to positively impact the lives of more than 9,000 sarcoma patients.

Having lived with sarcoma myself and having interacted with thousands of patients over the last eight years, I have seen first-hand the numerous challenges sarcoma patients face.

Before discussing those challenges, it is important to understand what sarcoma is.

What Is Sarcoma?

Sarcoma is a rare and high-grade cancer that arises from bones and soft tissues such as muscles, fat, nerves, and blood vessels. It can occur in any part of the body and often appears as a lump or swelling, which may be painless or painful.

Sarcoma can affect any age group—children, adolescents, young adults, and the elderly. It is a highly heterogeneous cancer, with around 200 subtypes. Because it is so rare, patients diagnosed with sarcoma often feel isolated and lonely, and many struggle with mental health issues.

Challenges Faced by Sarcoma Patients

Sarcoma patients face multiple challenges, starting from the very beginning of their diagnosis.

Many patients experience misdiagnosis or late diagnosis. Often, they receive treatment from doctors who are not sarcoma specialists, which leads to inappropriate or incorrect treatment. Like any other cancer, early detection is crucial in sarcoma. Early diagnosis can save lives and, in many cases, save limbs.

Due to lack of awareness, patients usually first visit local physicians and begin incorrect treatment. By the time they reach tertiary cancer centres such as AIIMS, Tata Memorial Hospital, or Homi Bhabha Cancer Research Centre, the disease may have already spread. Once sarcoma becomes metastatic, curing the patient becomes extremely difficult.

Correct diagnosis is critical. Biopsy plays a very important role in sarcoma, and accurate pathology done at experienced tertiary centres can significantly improve prognosis. Sarcoma patients must take treatment only from sarcoma specialists who work in a multidisciplinary team involving pathologists, medical oncologists, radiation oncologists, and radiologists. Wrong treatment at the initial stage can have lifelong consequences, including amputation.

These are major administrative and medical challenges, but the struggles do not end there.

Emotional and Psychological Struggles

Emotionally, sarcoma patients go through immense turmoil.

Many patients ask, “Why me?”

Some experience suicidal thoughts and feel like giving up on life. The first questions that arise are:

“Will I survive?”, “Who will take care of my family if something happens to me?”

Because sarcoma often affects young adults, many compare themselves with peers who are progressing in their careers and feel left behind. Young women diagnosed with sarcoma worry about marriage and fertility, especially as chemotherapy can affect their ability to have children.

Patients undergoing chemotherapy also face body image issues—hair loss, eyebrow and eyelash loss, weight changes—which deeply affect their confidence. Many withdraw from social interactions, leading to further isolation and loneliness.

Financial, Logistical, and Social Barriers

Sarcoma treatment usually involves surgery, chemotherapy, radiation, or a combination of these. Treatment in private hospitals, expensive implants, or immunotherapy adds to the financial burden.

Patients from neighbouring countries like Nepal, Bangladesh, and others come to India for treatment and face severe logistical challenges—finding accommodation near hospitals, arranging visas, getting appointments, and navigating an unfamiliar healthcare system.

Many patients do not receive adequate family or employer support. Some lose their jobs after amputation or implant surgeries, which further worsens their financial stress. Relationship issues and lack of social support add to their suffering.

Thus, sarcoma patients face challenges that are physical, emotional, financial, administrative, and logistical.

Role of Sachin Sarcoma Society

Once diagnosed with sarcoma, patients must seek treatment at a good tertiary centre and should be part of a dedicated sarcoma support group like Sachin Sarcoma Society. We work to ensure that no sarcoma patient fights this disease alone.

Rarity of sarcoma does not mean neglect

Sarcoma patients should not suffer in silence just because their cancer is rare. Rarity must never mean neglect. There is an urgent need for doctors, hospitals, policymakers, insurers, diagnostic labs, NGOs, and the government to recognise sarcoma as a serious cancer that requires focused attention. Early referral to sarcoma specialists, correct biopsy and pathology at experienced centres, and timely treatment must become standard practice. Financial burden, delayed diagnosis, emotional trauma, and loss of livelihood can be reduced only when all stakeholders work together. Sarcoma patients deserve timely care, dignity, emotional support, and hope—and together, we can ensure that no sarcoma patient ever fights this disease alone.

Call to action – How Can We Make a Difference in Sarcoma Care?

To reduce barriers and improve outcomes, we must:

- Increase awareness about sarcoma among the general public
- Collaborate with doctors, government bodies, NGOs, diagnostic labs, insurance companies, and policymakers
- Conduct more patient education and caregiver programs
- Improve doctor training and referral systems
- Strengthen patient advocacy with the government
- Ensure timely referral of patients to sarcoma specialists
- Connect patients with each other for peer support
- Include dedicated sarcoma sessions in cancer conferences

When all stakeholders come together, there is hope that together we can be stronger than sarcoma and improve patient outcomes in our country.

Reach Out to Us

If you or your loved one is diagnosed with sarcoma, you are not alone.

📞7303827447 📧support@sachinsarcomasociety.org 🌐 www.sachinsarcomasociety.org

Remembering a Great Friend to the LRG – Chuck Korte

by LRG Staff

To so many in our community, Chuck was a beacon of hope. He was one of the very few long-term survivors from the original Gleevec (STI-571) clinical trial, which he joined in 2001. For decades, Chuck represented what was possible, and his story gave hope to countless patients and families facing a GIST diagnosis.

This past summer, Chuck was diagnosed with a secondary, aggressive cancer lymphoma. Despite this difficult turn, he remained surrounded by love, and he passed peacefully last night with his family by his side.

New Horizons
Long-Term Survivor Testimony

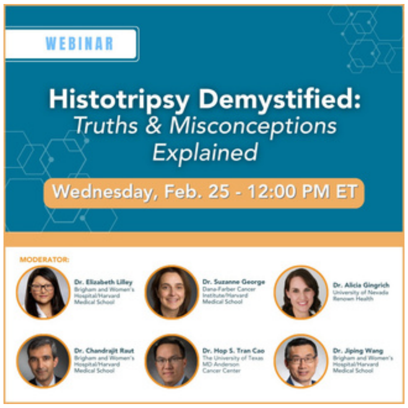
Long-Term Survivor Stories:
Chuck Korte & Dina Wiley

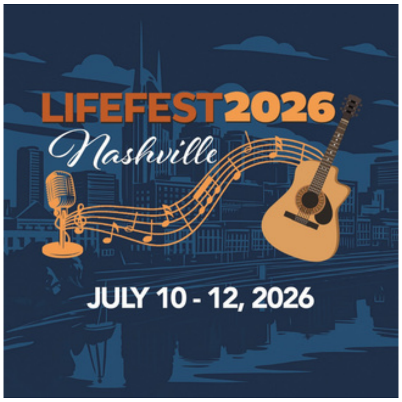
Chuck often reminded us, ***"It is a blessing to be alive; we can give thanks by being a blessing to others."*** He truly lived those words.

We hold Chuck's family close in our thoughts and hearts, and we honor his extraordinary legacy, one that will continue to inspire hope for years to come.
As is our tradition, please light a candle to honor the incredible legacy of this wonderful man.

> Chuck's Memorial Service is this Saturday March 14 at 2 pm ET online at YouTube.
> ***https://youtube.com/live/-vYoUEokQm8***

Featured Events:





Wrapping Up 2025...

2025 LRG Highlight Video

As we close 2025, we reflect on a year of meaningful impact: expanding education with three GIST Days of Learning, including our first in Spanish; advancing research through published our first in Spanish; advancing research through published papers and major conference presentations; and raising awareness through nationwide fundraisers and Jerry Call's cross-country motorcycle ride for GIST. We also welcomed 500 new members, strengthening our global GIST community, and honored Laura, our retiring Deputy Executive Director, for her lasting impact. As we look to the new year, we remain hopeful, energized, and committed to moving closer to a cure together.

Impact Report 2025

Read more about how The Life Raft Group empowers, educates and advocates for the GIST community.

Click on the report to view!

IMPACT
2025

The Life Raft
GROUP

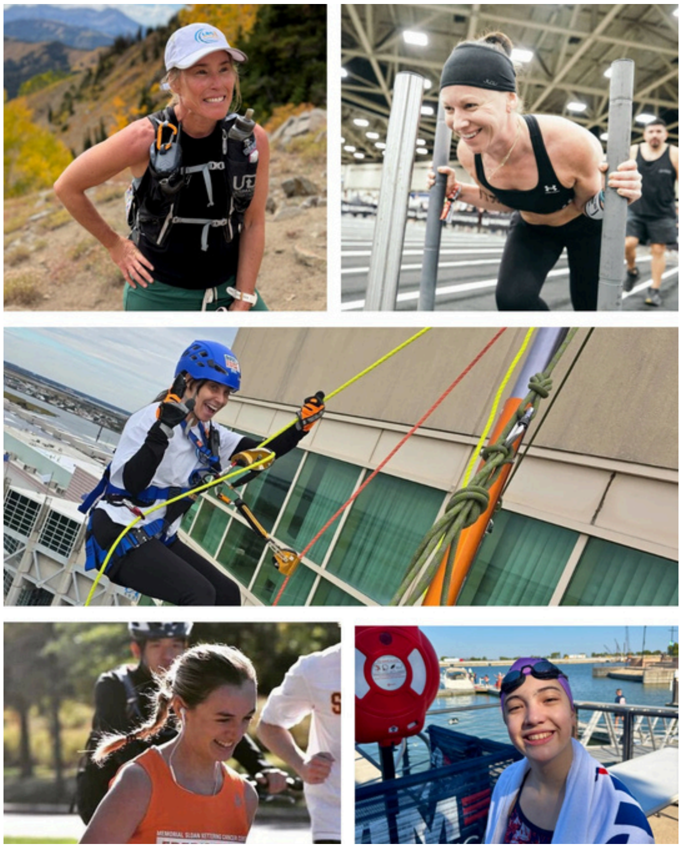
TGCT
Support

GCT
Support

LIPOSARCOMA
SUPPORT NETWORK

ENSURING NO ONE FACES A RARE DISEASE ALONE

...and Picking Up the Pace in 2026!



The LRG Athletes made quite an impression in 2025 with Natalie, Heather, Evelyn, Toni and Rachel's events - filled with adventure and competition. They did an amazing job of raising awareness and thousands of dollars for GIST research!

This year, Toni has already committed to a new marathon goal in April!

Become an LRG Athlete this year - have fun & support our community!

BE AN LRG ATHLETE!

SUPPORT & CONNECTION

GIST Chat

GIST Mentor Program

Online Support Groups

SDH Support Group

GIST Days of Learning

Webinars

Life Fest

Volunteer

YouTube Playlists

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