

ANNUAL REPORT 2025

Letter from the Executive Director

Sara Rothschild, Executive Director, *The Life Raft Group*

Dear Friends,

At The Life Raft Group, our mission has always been clear: to improve outcomes and quality of life for people living with GIST and to ensure that no patient faces this disease alone. As our work has evolved, we have also extended our model of support, research, and advocacy to additional rare disease communities (Tenosynovial Giant Cell Tumor, Giant Cell Tumor of the Bone, and Liposarcoma) that can benefit from the expertise and infrastructure we have built.

This past year, that mission was carried forward through the strength of our community—patients, caregivers, clinicians, researchers, volunteers, donors, and partners who continue to believe that progress is possible. For many patients, one of the greatest challenges remains access to specialized care. Because GIST is a rare cancer, too many individuals are diagnosed and treated without immediate connection to expert guidance. Patients often come to us overwhelmed, uncertain, and searching for answers at one of the most vulnerable moments of their lives. Our team works every day to bridge that gap—connecting patients to specialists, helping them understand mutational testing and treatment options, supporting second opinions, and offering the reassurance that they do not have to navigate this journey alone.

Community remains at the heart of our work. Rare disease can bring isolation, and one of our proudest accomplishments is creating a place where patients and families find connection, mentorship, and hope. In 2025, we welcomed patients and caregivers through our GIST Days of Learning educational programs in cities including Houston, Boston and Los Angeles, opened our New Jersey office to the community, and expanded outreach events that brought patients together face-to-face (such as Jerry's motorcycle Ride Across America!). These moments of connection matter deeply because they remind every patient that they are part of something larger than their diagnosis.

We also continued to expand our impact in research. Our patient registry and tissue bank remain among the most important resources in the GIST field, capturing data that advances scientific understanding and improves care. In 2025, Life Raft Group-supported work contributed to publications on genomic testing and SDH-deficiency in GIST, as well as innovative research exploring new vulnerabilities in imatinib-resistant disease. These efforts reflect the power of patient-driven data to influence science and accelerate new treatment pathways. We also funded three researchers with \$60,000 in grants (Dr. Matthew Hemming, UMass Chan Medical School; Dr. Inga Marie Schaefer, Brigham and Women's Hospital; Dr. Jason Sicklick, UC San Diego Moores Cancer Center) to advance their research efforts, an especially meaningful investment at a time of declining federal funding for research at their respective institutions.



This year, we also strengthened collaborations across institutions and disciplines. In rare diseases, progress depends on breaking down silos, bringing experts together, and moving ideas into action. Whether supporting global partnerships, convening tumor boards for complex cases, advancing awareness initiatives such as GIST Awareness Day and Sarcoma Awareness Month, or helping launch innovative research efforts, The Life Raft Group continues to serve as a trusted connector and catalyst. We had launched a petition this past year when we saw a promising drug that was not going to be pursued further by a pharmaceutical company. We stepped up to say, "This drug deserves a second chance! If not us, then whom?"

We are equally committed to ensuring that progress reaches every patient. Through the continued work of our Health Equity Council, we have focused on expanding access to underserved communities, increasing awareness, and helping more patients find the specialized care and support they deserve. We even extended that outreach internationally, working with the Chinese Organization for Rare Disorders to convene a meeting for TGCT patients across the region.

Yet much work remains. We still need better treatments, more equitable access to care, stronger support for underserved communities, and ultimately, a cure. We know that persistence (both scientific and human effort) is what moves the field forward. None of this would be possible without your generosity and trust. Every donation, every hour volunteered, every shared story, and every partnership helps create real change for patients and families around the world.

As we look ahead, we do so with optimism and determination. With continued investment in research, patient support, education, and innovation, we believe the future for GIST patients and for others facing rare diseases can be brighter than ever before.

Thank you for standing with us and helping power this mission.

With gratitude,

Sara Rothschild



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About The Life Raft Group

The Life Raft Group (LRG) began in 2000, when a handful of patients in the early Gleevec trial started sharing their experiences online. Many patients had been misdiagnosed with leiomyosarcoma and were just now finding out they had an entirely different cancer – gastrointestinal stromal tumor, or GIST. Sharing their stories and experiences online helped them in a variety of ways, including gaining much-needed support while facing a rare disease and managing the side-effects of a new drug. In the next two years, this group formed a newsletter and website to share information with an even wider audience, before formally incorporating in June 2002. Over the years, the LRG has grown immensely, meeting the challenges facing GIST patients and caregivers and the research community every step of the way.



Our Mission and Vision

The LRG 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.



DEVELOPMENT

Strengthening Community Through Education and Connection

Knowledge and connection are the best tools against the uncertainties of a rare disease. In 2025, we continued to strengthen one of the most important pillars of our mission: helping patients and caregivers feel informed, connected, and supported throughout their journey.

Through our Development Team's work in patient education, support programming, fundraising, and volunteer engagement, we focused on creating meaningful opportunities for the community to learn from experts and from one another.

Bringing Education Directly to Patients

This year, our commitment to patient empowerment and education came to life through three successful GIST Days of Learning (GDOL) events, bringing together patients, caregivers, clinicians, and researchers for a day of education, conversation, and connection.



More than 200 attendees participated across these events, underscoring the need for accessible, specialized GIST education and community support.

Our 2025 programs included:

- A collaborative GIST Summit with GIST Support International and MD Anderson Cancer Center
- A GIST Day of Learning at UCLA
- A GIST Day of Learning at Dana-Farber Cancer Institute in Boston



These gatherings do more than share medical updates on the latest developments in GIST. They create space for patients to ask questions, hear directly from experts, and connect with others who understand the challenges of living with a rare cancer. For many attendees, it is the first time they realize they are not navigating GIST alone.

As we work toward our 2030 goal of enhancing community engagement and expanding our impact, these educational experiences remain a cornerstone of how we build a stronger, more informed, and more connected rare disease community.



Support That Changes Lives

A rare cancer diagnosis can feel overwhelming. Patients are often faced with unfamiliar medical terms, difficult treatment decisions, and a sense of uncertainty about what comes next. One of the most powerful forms of support can come from someone who has already walked that road.

In 2025, The Life Raft Group's GIST Mentor Program continued to provide one-to-one peer support for patients and caregivers seeking guidance, encouragement, and understanding from someone who knows what living with GIST is like. Our volunteer mentors offered more than information. They provided reassurance, practical insights, and the reminder that no one has to navigate GIST alone.

Whether helping a newly diagnosed patient prepare questions for a specialist, sharing experiences around treatment side effects, or simply listening during difficult moments, mentors served as trusted companions through every stage of the journey.

The program also strengthened the bonds within our community, bringing together individuals who understand the emotional realities of rare disease in ways few others can. As patients become survivors, and survivors become mentors, patients become empowered to impart their knowledge to others.

The GIST Mentor Program reflects our commitment to enhancing community engagement by creating meaningful connections that empower patients with both information and human support. Because in rare disease, lived experience can be just as valuable as medical expertise.



"It was so nice to talk to you today. I didn't feel as alone I've been the last seven months. Thank you so much."

- Kim C, GIST mentee

"Mentoring has brought to me a very soothing and personal gratification of giving back, helping others with the challenges of a new diagnosis, a potentially terminal disease. It's emotionally rewarding to realize the change."

- Jon T, GIST mentor

"Humans were never meant to live life alone. When I am mentoring others, we mutually help each other through the realization of our mortality, which is the most difficult reality faced in everyone's life."

- Jason D, GIST mentor



Competing for a Cause

In 2025, the LRG Athletes program grew into one of The Life Raft Group’s most inspiring expressions of our community. What began as a way to connect patients, caregivers, families, and supporters through movement quickly gained momentum, bringing people together around a shared purpose.

As we look ahead, we are excited to grow the LRG Athletes community, welcoming more participants, expanding opportunities to engage supporters, and continuing to turn movement into momentum for rare disease awareness and research.

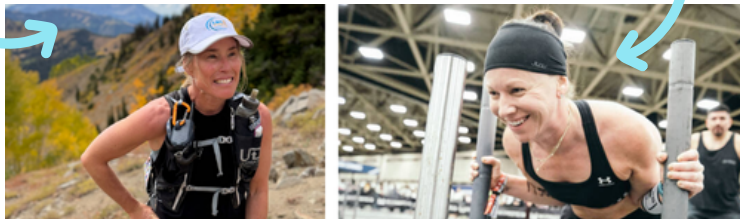
We are grateful to Natalie Power, Evelyn Chen, Heather Bliss, Rachel LoCurto, and Toni Pauwels, whose efforts raised nearly \$25,000 this year in support of The Life Raft Group’s mission.

“Thank you to all who supported me! A cancer diagnosis does not mean you can’t keep pushing your body and doing the things that you love! Thank you to The Life Raft Group to enhancing the lives of all GIST patients.”

“With this cancer being so rare, there aren't a lot of resources, but I found The Life Raft Group and couldn't be more thankful.”

**\$5,960
RAISED**

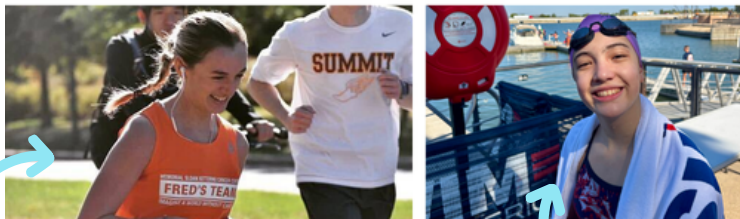
**\$11,600
RAISED**



“Why not rappel down a building? It's a fun thing to do, it's for a good cause, and it supports our LRG Athletes program. LRG Athletes is a community of people who support the LRG and do kind of extreme challenges.”

**\$2,845
RAISED**

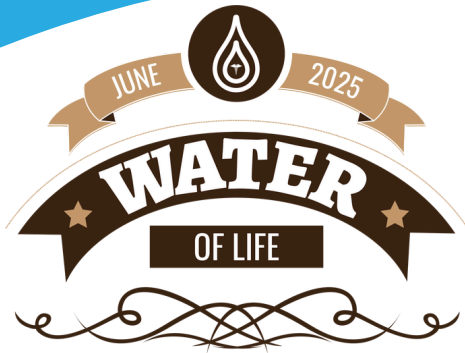
**\$2,120
RAISED**



“Every mile is for the GIST community. I run for the patients I've met, the stories I've carried, and the hope that together, we can push research forward and make sure no one faces this disease alone.”

“My grandma was such a vibrant, elegant, and loving person. Her life was cut short by this terrible disease, but I want to keep her spirit alive by helping others facing GIST.”

**\$1,700
RAISED**



Fundraising from the Heart

In 2025, The Life Raft Group's Water of Life events brought people together through genuine connection, generosity, and hope. Each gathering reflected a simple idea: when we unite, we strengthen the vital support network surrounding those affected by GIST.

The inaugural Water of Life whisky speed tasting event, held June 25 and 26, was shaped in part by Dr. Matthew Lurin's remembrance of his stepfather and his desire to create something meaningful in his honor. Over two evenings in New York City, supporters, patients, and friends bonded over a unique evening with a collective mission. Conversations focused on research, advocacy, and the vital role of grassroots support in rare disease. What stayed with many was the incredible warmth and energy formed in the room.



Later in the year, the 8th annual WOLF event once again united supporters in New York City. The evening centered on generosity and a common goal. Guests experienced a remarkable selection of rare and aged whiskies. Ultimately, the focus remained on people showing up for one another and for the GIST community. The evening continued at the Carnegie Club, where conversation and connection extended into the night, marking one of the most successful fundraisers since the COVID pandemic.

Combined, these Water of Life events raised \$60,000 in gross revenue, reflecting how a movement is built and sustained through remembrance, gathering, and dedication. They also support our focus on deepening engagement and bringing families closer across the GIST community.



A Ride for Cure

Jerry Call, long-time Life Raft Group community member and data analyst, took his support on the road in 2025 for a unique awareness and fundraising campaign. During a summer motorcycle journey across the country, he combined personal time with a mission to raise awareness for GIST and connect with the broader community.

Over the course of his trip, Jerry traveled through 18 states and met with more than 100 patients and caregivers. He also visited cancer centers, spoke with researchers and clinicians, and helped bring visibility to GIST in each place he stopped. Along the way, he organized small fundraisers and conversations that kept the focus on education, connection, and support.

Jerry completed his cross-country ride on June 27, raising more than \$10,000 for GIST research. His journey reflected the impact of one person using their time and voice to strengthen community connections across distance.



DEVELOPMENT
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Our Newest Fundraiser

The year's fundraising efforts also introduced a new community-driven event. The Life Raft Group's first Texas Hold'em Poker Tournament was created by the LRG, as a way to build local engagement aligned with our mission and goals.

Hosted at the Oakland Elks Lodge in Oakland, NJ, in partnership with Mike's Poker Tables, the evening brought together poker players, friends, and supporters for friendly competition and shared purpose. The focus stayed on connection as much as the game itself. People shared stories, encouraged one another, and came together in support of individuals living with GIST.

The tournament raised nearly \$3,000 in net proceeds, helping fund patient resources and support services. It also set the stage for future community-based events that expand how people can engage, give, and stay connected to the mission.



OTHER FUNDRAISERS



Supporters hosted 33 Facebook fundraisers in 2025 and raised over \$10K for GIST and TGCT.



The GEMs giving program continued to provide steady, community-powered support throughout the year, helping ensure reliable funding for patient resources, research, and outreach. We now have 49 monthly donors. Our goal is to double this number by 2030.

In 2025, our fundraising efforts strengthened a more sustainable and community-driven model of support for The Life Raft Group. Through events, monthly giving, and personal fundraisers, we expanded engagement while ensuring consistent funding for patient resources, research, and advocacy. By deepening these connections, we've built a more resilient foundation for the GIST community and established a clear path forward for the coming year.

INFORMATION, EDUCATION & ADVOCACY

Our Programs Team works to create educational webinars for GIST patients led by experts in the sarcoma field on subjects that matter the most to patients and caregivers.

In 2025, The Life Raft Group expanded its educational reach online like never before, hosting 12 webinars on key topics impacting the GIST community. For the first time, we offered several sessions in Spanish, breaking language barriers and making vital information more accessible to a broader audience. Expert speakers led discussions on nutrition after GIST surgery, palliative care, and holistic healing - all presented in both English and Spanish.

Additional sessions covered financial support and Medicare updates, caregiving resources, and the latest clinical insights from major conferences such as ASCO and CTOS. These webinars reflected our ongoing commitment to empower patients and caregivers worldwide through education, inclusion, and expert-driven dialogue.



WEBINARS 2025

Exploring the SARC 044 Trial

Dr. Candace Haddox
Dana-Farber Cancer Institute
Date: January 8, 2026

Nutrition After GIST Surgery - English

Maria Camila Gomez, Nutritionist
Date: March 28, 2025

Nutrition After GIST Surgery - Spanish

Maria Camila Gomez, Nutritionist
Date: March 28, 2025

Palliative Care and GIST – English

Dr. Grant Smith, Stanford Health Care
Date: May 6, 2025

Palliative Care and GIST - Spanish

Olivia Nerimora, Stanford Health Care
Date: May 6, 2025

Holistic Approaches to Healing in Harmony

Carolina Williams, GIST Patient Advocate
Date: May 13, 2025

Updates from ASCO

Dr Herbert Loong
Chinese University of Hong Kong
Date: June 19, 2025

Navigating Financial Support & Medicare Changes: Need to Know in 2025

Jennifer Noonan, Accessia Health
Date: June 30, 2025

GIST Awareness Day Fireside Chat

Dr. Jason Sicklick, UCSD Moores Cancer Center,
and Dr. John Glod & Dr. Andrew Blakely, NCI NIH
Date: July 11, 2025

Making Cents of Caregiving

Al Berg, AARP
Date: August 12, 2025

ctDNA and the INSIGHT Trial

Dr. Jon Trent
UM Sylvester Comprehensive Cancer
Center, Miller School of Medicine
Date: November 10, 2025

Updates from CTOS

Dr. Pawel Sobczuk
Vall d'Hebron Institute of Oncology
Date: December 3, 2025

New Horizons Global Advocate Academy Course



Sarcoma
Patient Advocacy
Global Network

INFORMATION, EDUCATION
& ADVOCACY
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Advocacy in Action

Advocacy at The Life Raft Group ensures patients and caregivers have a voice in the systems that shape their care. It connects lived experience with research and policy to improve access, understanding, and outcomes. In 2025, this work continued to advance our strategic focus on stronger partnerships, better education, and reduced barriers to care.

Global Advocate Academy Course

Co-led by The Life Raft Group and the Sarcoma Patient Advocacy Global Network (SPAGN), New Horizons GIST convenes representatives from several countries to discuss critical information about GIST that impacts the global GIST patient and medical communities.

The New Horizons GIST Consortium has created a Global Advocate Academy Course (GAAC) targeted towards GIST patients, caretakers, oncologists, researchers, and organization representatives located worldwide. This course focuses on building skills for effective advocacy and implementing change across government, research, and treatment access.

In 2025, we added three new mini-courses in the following topics: Coalition Building, Evidence-Based Advocacy, and Barriers to Sarcoma Treatment. There are plans to expand the course list as needs are identified within the global advocacy community.

15th Annual SPAGN (Sarcoma Patient Advocacy Global Network) Conference

The conference was held in the US for the first time, in Washington, D.C., bringing together more than 120 patient advocates, experts, and partners from nearly 30 countries to connect, learn, and collaborate. Sessions focused on international collaboration, patient-partnered research, clinical trial access, the value of patient data, and disparities in sarcoma care, along with disease-specific tracks for soft tissue and bone sarcomas, GIST, and desmoid tumors.

These conferences are critical for advocacy groups because they strengthen global partnerships, elevate the patient voice in research and care, and help turn shared knowledge into more equitable access and better outcomes for patients worldwide.

Notably, at this event, Norman Scherzer, Co-Founder and Executive Director Emeritus, was honored with a **Lifetime Achievement Award** from SPAGN in recognition of his decades of advocacy on behalf of the GIST community. We are proud to carry forward the work he built with such dedication, and grateful that the global community took this moment to recognize the extraordinary impact of his contributions.



Norman Scherzer
Executive Director
Emeritus



Working Toward Health Equity for All

Established in 2024, the LRG Health Equity Council remains a driving force for inclusion and access within the GIST community. Though we mourn the loss of one of our dedicated members, Martina Will, her legacy continues to inspire our mission. In 2025, the Council identified key areas of focus, including expanding outreach to rural regions across the southeastern United States, ensuring patients receive our life-saving support as soon as they are diagnosed.

This year, the LRG team visited 17 cancer centers in the Southeast, both in person and virtually, and enlisted volunteers to help build a sustainable outreach network that keeps smaller centers connected and facilitates faster patient referrals. Another priority area is improving access for veterans with rare cancers. Our goal is to collaborate with the U.S. Department of Veterans Affairs (VA) to ensure that these patients are informed and supported through every step of their care journey.

“There’s a lot of strength knowing you are not alone in this. Finding LRG allowed me to feel like there were other unicorns out there in that wilderness with me. Especially the more I connected with the LRG at virtual and in person events, the more I realized that I had a really strong advocate in the LRG, that they were out there talking to the doctors. They were raising money for research. They were trying to bring new treatments into clinical trial phases. I don’t have the power or the energy to do that on my own, but knowing that there’s this organization, this small but fierce group of warriors. They are incredibly knowledgeable, and they really fight for us.”

- Martina W, GIST patient



Taking the Fight to DC

2025 brought many policy changes to the United States concerning healthcare and in response the Sarcoma Foundation of America created the Sarcoma Advocacy Weekend in Washington, DC. Representatives from many sarcomas organizations including the LRG for GIST patients attended and spoke with members of Congress about federal funding for sarcoma research, access to treatment and clinical trials, and health insurance policy issues.

This kind of collaboration is helping shape where advocacy goes next. When patients, caregivers, and organizations come together, it creates a stronger, more consistent voice in policy discussions. It also helps ensure that what people are experiencing in real life is reflected in decisions about funding, access, and care.

In 2026, this work will continue to focus on expanding participation, strengthening partnerships with national advocacy groups, and increasing opportunities for patients and caregivers to engage directly in policy conversations that impact research and treatment access.

DATA MANAGEMENT & RESEARCH

In 2025, the Data Management & Research team continued to strengthen how patient data is used to improve understanding, care, and outcomes in GIST. We participated in more than a dozen global collaborations to advance research, patient advocacy, and treatment innovation. With these partnerships, we have contributed to expanding scientific knowledge, improving patient care, and supporting innovative treatment approaches.

Through these global research collaborations and registry work, we expanded the reach of our data while keeping the patient voice at the center of every effort. This work supported our strategic goals of advancing research, improving access to expertise, and connecting patients to better care.

We extend our deepest gratitude to the clinicians, researchers, medical professionals, and advocates whose dedication and expertise make this progress possible. Together, we are driving meaningful change for patients worldwide.

Connecting Patients to Care and Expertise

Our team continued to support patients in practical and meaningful ways. More than 350 patients were connected to GIST specialists, supported through insurance appeals, and included in conversations with researchers and industry partners. Our membership increased from 309 in 2024 to 484 in 2025, representing an approximate 56.6% year-over-year increase. These connections ensure that lived experience continues to shape research priorities and treatment development.

Growing the Registry and Community Impact

In 2025, participation in our Patient Registry continued to grow, strengthening the foundation for future research. More patients contributed data, more institutions engaged with our work, and more findings were translated into actionable insights. This growth expands what is possible for future studies and strengthens the global GIST knowledge base.

We also expanded participation in global research collaborations, strengthening the role of real-world data in advancing the field and improving how GIST is studied and understood.

On behalf of the Data Management and Research Team, we extend our deepest gratitude to the patients and caregivers who participate in and contribute their information to our patient registry. Despite the many challenges of living with GIST, their dedication makes our work possible, none of our accomplishments would be achievable without them.



Advancing Research and Scientific Impact

Highlights of our work in 2025 include:

- Our work was accepted for an oral presentation at the Connective Tissue Oncology Society (CTOS), a leading conference in sarcoma research. The presentation focused on young adult and pediatric patients and examined the diversity of mutational profiles and clinical outcomes in these under-studied groups with limited available data.
- In addition, four abstracts were accepted and featured at the meeting. All were published, three were presented, and one received an award for Best Poster in the GIST category.
- Data was submitted and we participated in the first outcome meeting for a new GIST risk assessment tool.
- An SDH-deficient GIST database linked to frozen tissue was launched, enabling a comprehensive understanding of this GIST subtype across the full spectrum of molecular and clinical features.
- Contributed to collaborative research projects on:
 - First-line patient outcomes
 - Mutational impacts, including rare GIST subtypes like SDH-deficient GIST, NF1, and BRAF.
 - Explored the dynamics of generics and side effects when compared to brand name.
 - Achieved a record-breaking number of paper submissions in 2025, demonstrating unprecedented research productivity and impact.
- Published a record number of scientific papers in LRG's history, including in Nature Cancer and JAMA, expanding the organization's global research influence.
- Hosted four virtual tumor boards, including the first joint GIST and liposarcoma tumor board, driving cross-disease learning and expert engagement.
- Analyzed real-world registry data to explore the impact and outcomes of multiple therapies, producing actionable insights for patient care and research.
- Engaged with multiple institutions across the U.S. to raise awareness of GIST and strengthen nationwide research and patient care collaborations.
- Presented patient concerns to multiple pharmaceutical companies to ensure the patient's voice is central in research and drug development decisions.

DATA MANAGEMENT & RESEARCH

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Looking Ahead to 2026

In 2026, our focus is on scaling impact. With the anticipated launch of a new, advanced GIST Patient Registry, we will increase patient engagement, making it easier for individuals to share their data, access their medical information, and contribute to GIST research.

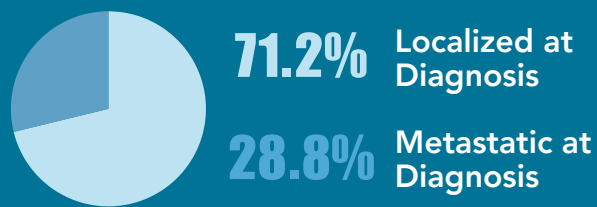
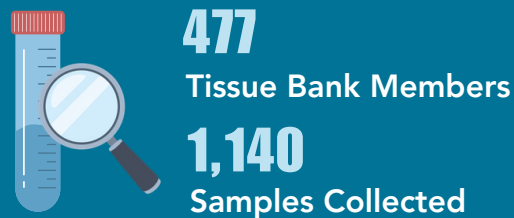
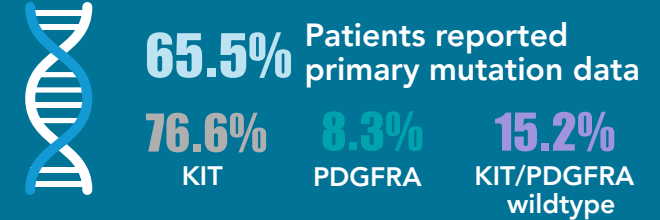
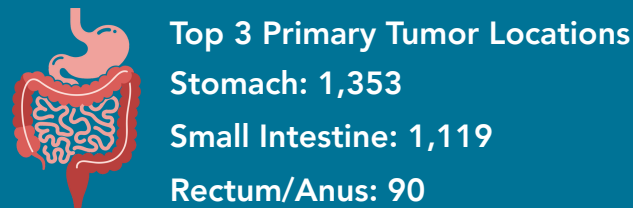
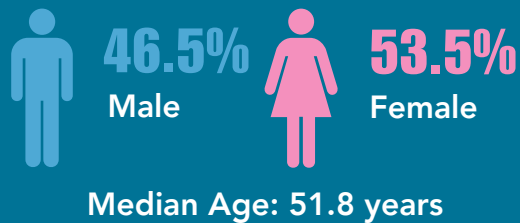
This expansion also includes growing global data partnerships, improving real-time use of registry insights, and strengthening systems that connect patients to expertise more quickly. The goal remains the same: turning data into action that improves care for every patient with GIST.

Patient Registry in Review


Through our ongoing global patient registries, patients voluntarily share their medical and treatment data to deepen the understanding of the disease and accelerate research progress.

Patient-driven data fuels research and supports better treatment outcomes.


DATA MANAGEMENT & RESEARCH
CONTINUED FROM PAGE 15





Global participation spans 113 countries, advancing worldwide collaboration.



Top tumor sites: Stomach, Small Intestine, and Rectum/Anus.



Over 71% of tumors were localized at diagnosis.



High-risk recurrence represented in over 50% of known cases.

RESEARCH FUNDING

Funding the Future of GIST Research

In 2025, The Life Raft Group provided research funding to three exceptional investigators advancing important work in GIST. These projects represent meaningful progress toward improving outcomes and expanding treatment knowledge for patients.

This investment reflects our strategic focus on increasing support for research that directly impacts the GIST community. As we grow our research funding efforts, studies like these remain central to how we move the field forward and create new possibilities for patients and families. Together, we continue to drive research forward, one discovery at a time.



Dr. Inga-Marie Schaefer
Brigham and Women's Hospital

"Exploiting Cell Cycle Perturbation in GIST for Therapeutic Targeting"



Dr. Matthew Hemming
UMass Chan Medical School

"Identification of novel therapeutic strategies for succinate dehydrogenase (SDH)-deficient gastrointestinal stromal tumor."



Dr. Jason Sicklick
UCSD Moores Cancer Center

"Translating RNAseq signatures to treatment of GIST."

RARE DISEASE INITIATIVES BEYOND GIST



Throughout 2025, TGCT Support continued to grow in reach and impact, reaffirming its deep commitment to supporting and empowering the TGCT community. As part of this year's goal to advance medical education efforts, we delivered three CME courses that reached clinicians across regions, while a UK-based consensus paper helped establish important standards of care based on regional needs. These initiatives supported both

global and national healthcare systems, equipping providers with the knowledge needed to deliver thoughtful, evidence-based care. This was also the first consensus to develop a criterion for what patients do not benefit from surgery, a true unmet need in this space!

Our work extended globally as we traveled to China to address unmet needs and close critical gaps in understanding. Through partnerships with clinicians, scientists, organizations, and patients, we strengthened collaboration and advanced care across the spectrum, ensuring no community was left behind. Research remained a central focus of our efforts. We proudly presented 3 research projects and submitted them for journal publications, all guided by the patient's voice. In parallel, we launched additional studies aimed at addressing inequities and improving access to multidisciplinary care.

Our outreach and community engagement continued to grow throughout the year. Our community has grown to over 2,500 patients, including our patient registry, which includes patients from 58 countries. Support resources also flourished, including the development of a dedicated cookbook and a comprehensive FAQ. We reached an important milestone with 250 support groups and delivered 4 new educational webinars covering topics from pathology to advancements in care. Each program was designed to empower patients, caregivers, and providers with meaningful, accessible knowledge.

Progress was further amplified through increased social media engagement, including the launch of a TikTok that generated more than 10,000 views and contributed to a 140% increase in website engagement compared to the previous year.

As we continue to build on this momentum, we remain focused on expanding impact, advancing care, and driving meaningful change worldwide.



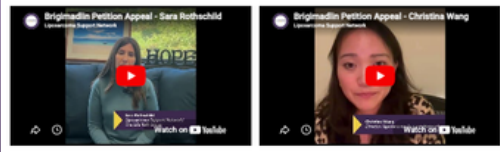
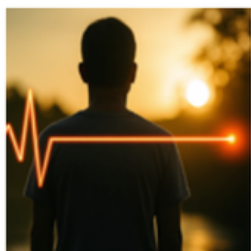
This year marked our first full year supporting the liposarcoma community, and boy, have we been busy! We continue to see strong growth across all of our programs and initiatives and have welcomed hundreds of new members.

Early in 2025, we established the LSN Medical Advisory Board, bringing together experts to guide research priorities, strengthen medical understanding, and advance patient support and advocacy in hopes of driving meaningful progress in the fight against liposarcoma. The inaugural meeting launched our collaborative work focused on liposarcoma care and research.

Save Brigimadlin. Save Lives.

We are physicians, scientists, and patient advocates fiercely committed to the survivorship of people with rare cancers. Our community profoundly values Boehringer Ingelheim's work in developing a drug for liposarcoma, a rare and fatal cancer. Yet we are deeply alarmed by the decision to terminate the further development of brigimadlin (BI 307282) and to not move forward to explore future studies or partnerships.

For patients with dedifferentiated liposarcoma (DDLPS), this is a devastating blow. Brigimadlin is not a failed drug. Although the Phase II trial (BRIGADIAN) did not meet its primary endpoint, brigimadlin showed clear benefit, delivering objective responses and prolonged disease control that offer real hope in a rare, deadly cancer with few treatment options.



After Boehringer Ingelheim's decision, in late 2024, to halt further development of brigimadlin for dedifferentiated liposarcoma (DDLPS), our team went to work and spent 2025 embarking on an advocacy campaign to explore potential paths forward for this drug. With the backing of experts, specialists, advocacy groups, and the liposarcoma community, we successfully gathered well over 2,000 signatures for our petition and continue to encourage Boehringer Ingelheim to pursue an alternative path to keep development alive and advancing toward regulatory approval. We remain steadfast in the need for more treatment options for liposarcoma.

Throughout the year, we have been actively working on the development of our patient registry and are currently in the process of finalizing and securing approval for the data fields. This registry is a critical,

first-of-its-kind resource for the liposarcoma community and has been designed to deepen the understanding of the disease, inform research priorities, and strengthen our advocacy work. We are eager to bring this important initiative to the community and look forward to its launch in 2026.

LSN's first virtual tumor board was held in October. This meeting provided a vehicle for leading experts worldwide to convene and discuss challenging cases in a secure virtual environment while serving as an educational resource for local physicians to understand the complexities of this rare disease. By facilitating this collaborative forum, we reinforced our commitment to patient-centered care and the power of expert teamwork in navigating difficult medical decisions.

We have deepened our connections in our support groups, creating a meaningful space for patients to connect. Through regular meetings and facilitated discussions, these groups fostered peer-to-peer support, reduced isolation, and ensured participants had access to trusted information and resources. With so much success in our patient groups, we launched a dedicated caregiver support group in early 2026.

RARE DISEASE INITIATIVES
BEYOND GIST
CONTINUED FROM PAGE 18



In addition, we hosted a series of educational webinars covering topics with liposarcoma-specific information to general support and wellness, delivering timely, accessible content to individuals around the world.

We also had posters at the annual Connective Tissue Oncology Society (CTOS) medical conference, sharing our insights and initiatives with leading experts in the field. These presentations allowed us to contribute to ongoing discussions, foster collaboration, and highlight the needs and experiences of the liposarcoma community on an international stage.

Supporter Stephen Wang turned this year's Cleveland Half Marathon into a powerful tribute to resilience, raising awareness and funds for liposarcoma research and support. Just one year after relearning how to walk following ACL surgery, Stephen crossed the finish line in honor of his sister Christina, and helped raise more than \$4,000.

Together, these efforts reflect our ongoing commitment to education, advocacy, and support for the liposarcoma community. Each accomplishment reinforces our belief in the power of collaboration and knowledge to make a real difference.

These achievements give us hope for the future, and through our continued dedication, we can improve outcomes, amplify patient voices, and provide meaningful guidance and resources for everyone affected by this disease.



RARE DISEASE INITIATIVES BEYOND GIST

CONTINUED FROM PAGE 19

LIPOSARCOMA SUPPORT NETWORK

The Liposarcoma Support Network (LSN) is committed to enhancing the survival and quality of life for people living with liposarcoma through patient-powered research, education and empowerment, global advocacy efforts, and guiding their journey toward a cure.

THIS YEAR'S ACHIEVEMENTS

PERSONALIZED SUPPORT FOR MEMBERS
Our community has grown to nearly 200 members from around the globe, each navigating a unique liposarcoma journey. Every new member receives personalized guidance and resources needed to understand the complexities of this rare disease. This support ensures that individuals can face their diagnosis with greater clarity and confidence.

PATIENT SUPPORT GROUPS
Our support group, which meets bi-weekly, offers emotional support, practical guidance, and valuable information that helps others feel less alone and more empowered throughout their journey.

NEW MEDICAL ADVISORY BOARD
The LSN Medical Advisory Board (MAB) was formed and held its inaugural meeting on May 30, 2025, in Chicago, IL. This powerful moment officially launched collaborative work with some of the leading minds in liposarcoma care and research.

EDUCATIONAL RESOURCES
In addition to up-to-date information on our website, LSN held three expert webinars this year, has scheduled our first Liposarcoma Day of Learning in February, and created a liposarcoma track at Life East 2026 in Nashville, TN, for patients and caregivers.

VIRTUAL TUMOR BOARD & REGISTRY
In October, we held our first Virtual Tumor Board in conjunction with The Life Raft Group, bringing together experts and clinicians to collaborate on a complex liposarcoma case. We are also preparing to launch a dedicated, global Liposarcoma Patient Registry.

ADVOCACY INITIATIVE FOR DRUG DEVELOPMENT

SIGN THE PETITION

PETITION TO CONTINUE DEVELOPMENT OF BRIGIMADLIN

While our community deeply values Boehringer Ingelheim's work in developing brigimadlin (BI 907828), a drug that has brought hope to patients with dedifferentiated liposarcoma (DDLS), we are alarmed and profoundly disappointed by their decision to halt further development.

*The company will continue providing the drug to patients who were already enrolled in previous brigimadlin trials but no new patients will have access.

BRIGIMADLIN IS NOT A FAILED DRUG
Although the BRIGHTLINE clinical trial for brigimadlin did not meet its primary endpoint, it delivered objective responses and prolonged disease control in a cancer with limited treatment options.

TO PATIENTS, THIS DRUG REPRESENTS HOPE
Ending further development is unacceptable and abandons patients whose lives depend on progress. This situation demands Boehringer Ingelheim pursue an alternative path: external partnerships, licensing, or academic collaborations to keep development advancing toward regulatory approval.

KEEP BRIGIMADLIN ALIVE. ACT NOW. SAVE LIVES.

LIPOSARCOMA SUPPORT NETWORK A MEMBER OF **The Life Raft**

LIPOSARCOMA SUPPORT NETWORK | @liposarcosupport | @liposarcosn

COMMUNICATIONS

Expanding Reach, Strengthening Connections

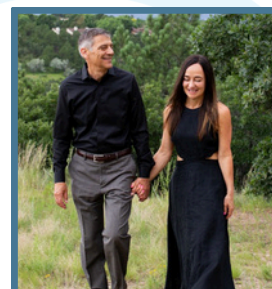
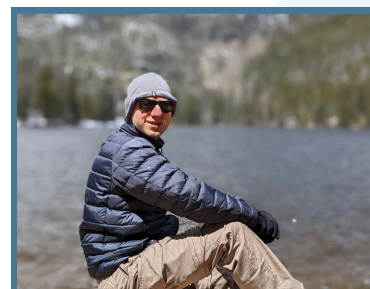
This year, the Marketing & Communications team focused on advancing the LRG's strategic priorities by expanding awareness, strengthening community engagement, and increasing access to trusted patient education.

To support our goal to expand our impact, we significantly increased our digital presence across social media platforms, including LinkedIn, YouTube, Facebook, Instagram, and Reddit allowing us to reach broader audiences and connect with more patients, caregivers, healthcare professionals, and advocates. Through educational campaigns, patient stories, videos, webinars, and awareness content, we worked to ensure more people could discover Life Raft Group resources earlier in their journey. Featured campaigns for the year focused on clinical trials awareness, biomarker testing, and advocacy issues.

We also developed new patient-facing educational materials designed to empower informed conversations between patients and their oncologists. These brochures enable patients to share information about our resources, clinical trials, side effects and other valuable information for patients and their care team.

To further enhance community engagement, we launched educational and awareness campaigns across social media to spark conversation, encourage participation, and build a stronger sense of belonging within the GIST and rare disease communities. By sharing patient voices and creating meaningful opportunities for engagement, we continued growing a more connected and informed community. We encourage patients to share their stories with our community via our channels and platforms, and regularly post content to support their journey.

Looking ahead, we remain committed to growing our reach, strengthening patient education, and using communication as a powerful tool to expand awareness, advocacy, and hope. We remain focused on the goal that no patient faces GIST alone.



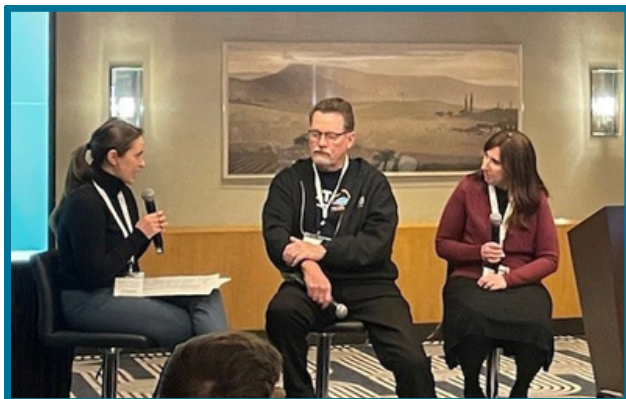


Giving Time From the Heart

The Life Raft Group's mission is supported by a global network of over 100 volunteers who generously give their time, expertise, and personal insight to support patients and caregivers around the world. From mentoring newly diagnosed patients to supporting education and outreach efforts, volunteers are central to our work with patients and caregivers.

Volunteers help expand our reach by guiding patients through some of the most overwhelming moments of their journey. Peer mentors provide one-on-one support, patient and caregiver leaders host support groups, and volunteers help connect individuals to trusted resources. Their efforts ensure more patients can access education, encouragement, and hope when they need it most.

They also strengthen community engagement in many ways. Volunteers write content, create social media awareness campaigns, support fundraising efforts, and help with behind-the-scenes office work that keeps programs running smoothly. Many patients and caregivers also share their own experiences in media interviews and forums with healthcare partners, bringing the patient voice directly into important conversations.



Volunteers contribute meaningfully to education, research, and health equity. Members of our Health Equity Council help identify barriers to care and improve access to information and resources for underserved communities. Others serve on our Science Team, reviewing current GIST studies and clinical trials to help translate complex research into information patients and caregivers can understand and use.

Volunteers are also key to our educational events, including GIST Days of Learning (GDOLs). Patient volunteers assist with event logistics such as registrations and attendee support, helping create welcoming and well-organized experiences. Medical professionals also volunteer their time to share expertise on treatment advances, research, and best practices in care.

Across all areas of our work, our volunteers bring their firsthand perspectives, professional knowledge, and deep commitment. Whether mentoring a patient, leading a support group, reviewing research, supporting events, or sharing their story, they help ensure patients and caregivers are supported, informed, and never alone.



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