



LIFE RAFT GROUP NEWS



Focused on improving the quality of life for people living with *gastrointestinal stromal tumor (GIST)* and other rare diseases.



JANUARY 2025

Navigating Rare Together

The LRG Strategic Plan

Carol Tordella, Sr. Director, Marketing & Communications

For 25 years, The Life Raft Group (LRG) has stood as a beacon of hope and support for those facing Gastrointestinal Stromal Tumors (GIST). Rooted in research, education, and advocacy, we've remained dedicated to improving the lives of patients and caregivers. Now, as we embrace a broader focus on rare diseases, our commitment grows stronger. Together, with innovation, collaboration, and the power of data, we're striving toward a future where rare diseases meet cures.

At the heart of everything we do are the people we serve. We're here to empower patients and caregivers, equipping them with the tools they need to confidently face their journeys. Our efforts remain patient-focused, prioritizing quality of life. We know progress requires innovation, and we recognize that real change happens through collaboration — with patients, families, researchers, and advocates working as one.

So, what's next?

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A Message From Our Executive Director



Dear Life Raft Group Community,

As we navigate a brand-new year, I am filled with hope and determination for what lies ahead. 2024 brought incredible milestones, and I'm thrilled to share some updates and exciting plans as we continue our mission to support and empower the GIST community.

One of the most significant accomplishments of 2024 happened behind the scenes with progress on enhancing our LRG Patient Registry. We're more than halfway through these updates, and I can't wait for you to experience the benefits this new platform will bring.

Have you ever wondered how many cases out there mirror yours? This new platform will let you explore the 'GIST landscape' while providing real-time updates about the broader GIST community. While our dedicated team will always be available to answer your questions and gather medical updates, this improved, user-friendly Registry will make it easier for you to share your information and gain valuable insights about how your GIST case compares to others. Our launch date is 4th quarter 2025, and we're eager for your feedback on this Registry upgrade!

Another highlight of 2024 was our involvement in groundbreaking collaborations, including the first GISTT Summit led by the Sarcoma Alliance for Research through Collaboration (SARC). This Summit underscored the power of bringing together senior and early-career researchers, oncologists, and patient advocates to explore the latest advances in GIST biology and treatment strategies. As a lead sponsor, we were excited to have contributed to this impactful event, which is helping to shape the future of GIST research.

Looking ahead, I'm thrilled to share some personal news about one of our own! This year, Jerry Call (a vital member of The Life Raft Group since its inception in 2000) is celebrating his 70th birthday this spring in an extraordinary fashion. Jerry will embark on a cross-country motorcycle journey to raise awareness about GIST and connect with our community.

For those who may not know, Jerry's commitment to this cause is deeply personal, inspired by his late wife Stephanie, who bravely fought GIST until her passing in 2014. Jerry's work as our data analyst has been instrumental in advancing publications that shape the field, and now he's hitting the road to connect and inspire our community face-to-face.

As Jerry travels across the country, he hopes to meet many of you—GISTers and medical experts alike. I'll be joining him at various stops, and we'd love to meet you if you'd like to connect along the way. (Jerry's route will be revealed in early spring).

Remember - your stories fuel our mission, and we look forward to hearing more from you throughout the year. Let's make 2025 a year of hope, discovery, and progress together!

With gratitude and determination,

Sara Rothschild

STRATEGIC PLAN

CONTINUED FROM COVER

So, what's next?

Our Vision for the Future

We imagine a future fueled by data and collaboration, where patients no longer face these battles alone, and the solutions they need are within reach. To make this happen, we've built a strategic plan to guide us over the next five years.



View Full PDF: bit.ly/StrategicPlanLRG

How We'll Navigate this Plan

Reach More Patients

- We're doubling the number of new patients we assist each year, ensuring support reaches diverse communities and no one feels left behind. Whether through expanded services or tailored outreach, we're committed to connecting with those in need.

Expand Our Scope

- While our roots are in GIST, rare diseases are vast and varied. We'll broaden our focus to include three additional diseases, meeting new communities where they are and learning how best to support them.

Strengthen Connections

- Building community is about more than numbers—it's about belonging. We aim to double the number of people actively engaging with our mission, from donors and volunteers to social media followers. We'll also create stronger platforms for patients to share their stories, give feedback, and feel truly heard.

Innovate in Data and Research

- Imagine a Patient Registry that doesn't just collect data but actively drives progress. We'll expand this resource to include three additional diseases and deepen our collaborations with researchers and clinicians. These partnerships will help unlock solutions that transform lives.

How We'll Stay Focused

To achieve these goals, we're guided by four strategic priorities:

1. Empowering Patients: Amplifying voices and fostering a sense of community and purpose.
2. Advancing Research: Supporting clinical trials and ensuring access to critical data.
3. Partnering for Change: Working with health agencies, industry leaders, and advocates to maximize impact.
4. Building for the Future: Growing our leadership team and focusing on health equity across the rare disease space.

Walking This Road Together

The road ahead won't be without challenges, but we're ready to meet them head-on. What remains constant is our dedication to the people we serve. At LRG, we believe no one should face a rare disease alone. **Together**, we'll navigate this journey with hope, driven by purpose, and inspired by a vision for a healthier future.

Tissue Donation - Give the Gift of Hope in 2025

Becky Owens, LRG Registry Consultant

The Life Raft Group has partnered with the National Institutes of Health to create a SDH Biobank. The project, spearheaded by Dr. Andrew Blakely at the NIH and Dr. Jason Sicklick at UC San Diego, supports the collection, analyses, storage and distribution of SDH-deficient GIST biospecimens for research.

SDH-deficient GIST patients can help with future medical research through the donation of their extra tumor tissue obtained during surgery. Tumor samples not used for testing or treatment are sometimes discarded, but with patient consent, these extra samples can be frozen and donated to the SDH Biobank.

Frozen tissue samples preserve the DNA and RNA information with better quality compared to formalin-fixed paraffin-embedded (FFPE) tissue samples due to the FFPE preservation process. Properly frozen tumor samples obtained during surgery enable researchers to propagate a working copy of the cancer cells that grow in the laboratory. This copy is called a cell model. A lack of SDH-deficient cell models has historically hampered SDH-deficient GIST research. By sharing your tumor tissue, you make it possible for researchers to make progress faster.

Each SDH-deficient GIST tumor sample is unique. Samples, accompanied by the data collected by The Life Raft Group for the SDH Biobank database, can help researchers better understand why treatments work for some patients but not for others, and to understand how to develop better treatments.

We are encouraging patients (and surgeons) to consider making a frozen tissue donation from SDH-deficient GIST surgeries to the Biobank. If you are aware of an upcoming surgery, please reach out to The Life Raft Group to discuss this option. The more advance notice given before a scheduled surgery, the better.

***There is a shared darkness amongst those who battle serious illnesses.
Tissue donation is free and offers light for the next person who ends up in this darkness.***



ATTENTION SDH-DEFICIENT GIST PATIENTS!

If you have an upcoming SDH-Deficient GIST Surgery, please consider making a fresh tissue donation to the SDH Biobank.

CONTACT:
BECKY OWENS, BOWENS@LIFERAFTGROUP.ORG

Tissue donation is free.
All it costs is a little planning & a little love.



Dr. Andrew Blakely

The LRG Welcomes Dr. Andrew Blakely to Our Medical Advisory Board!

Dr. Blakely has been a long-time supporter and collaborator of the LRG, contributing to research projects, educational events for patients, serving as a member of

the Pediatric & SDH-Deficient GIST Consortium & was honored as GIST Physician of the Year at Life Fest 2024.

His commitment to advancing care for rare diseases like GIST is reflected in his practice, where he focuses on gastrointestinal stromal tumors (GISTs) and peritoneal mesothelioma at the National Institutes of Health.

Through clinical and translational research, innovative surgical approaches, and collaboration with oncologists, he seeks to improve outcomes for patients with complex and rare cancers.

Dr. Blakely's expertise and dedication will be invaluable as we work together to better serve the GIST community, and we are honored to have him on our Medical Advisory Board.

Newest Board Member Brings a New Perspective to the LRG

We're excited to welcome Dr. Joseph Germino to The Life Raft Group's Board!

Dr. Germino is a retired medical oncologist who most recently served as the VP of Medical Affairs at Bayer, the pharmaceutical company behind Stivarga (regorafenib), a third-line treatment for GIST.

Before his time at Bayer, he treated patients with sarcoma and melanoma at the Cancer Institute of New Jersey. With experience in both patient care and the pharmaceutical industry, Dr. Germino brings a well-rounded perspective on healthcare from multiple angles.



Dr. Joseph Germino

"My first experience with the LRG was about ten years ago when we were working to get regorafenib approved. We connected with the team at LRG, and I was immediately impressed. Unlike most advocacy groups I'd worked with, LRG was incredibly sophisticated—analyzing patient data, collaborating with a science team, publishing a newsletter, and advocating effectively. It was a strong partnership, and they stood out as a truly impactful organization." shared Dr. Germino.

We're honored to have him on our board, bringing his expertise in drug development and his deep understanding of the challenges patients face. His insights will be invaluable as we continue to amplify the patient voice and make a lasting impact. We're looking forward to the fresh perspective and passion he'll bring to our advocacy efforts!

Ian & Kandee – In Memoriam

Laura Occhiuzzi, Deputy Executive Director

At The Life Raft Group, I've witnessed the power of connection in our patient and caregiver community. Sharing stories, struggles, and victories brings people together, building lifelong bonds and support systems that help navigate the emotional challenges of living with GIST. I have seen it firsthand. These connections are deeply personal to me, too. Friendships I've formed through LRG will last a lifetime. Yet, being part of this community also means facing loss.



Left to right: GISTer sisters Natalie Power, Carolyn Dewalt, Kandee Evans & Kelly Canepa.



Left to right: Laura Occhiuzzi, Ian Seah & Denise Evans (Sr. Dir. Data Mgmt. & Research).

Recently, we said goodbye to two dear friends, Ian Seah and Kandee Evans. Ian's passion for knowledge and dedication to helping create our new Patient Registry leaves a legacy we'll always treasure. Kandee, a loving wife, mother, and friend, treated the friends she met through the LRG like family. Her connection with her 'GISTer sisters', Natalie, Carolyn, Kelly, Suzanne, and Jess (aka snowflakes) was unbreakable—they supported her, and one another, every step of the way.

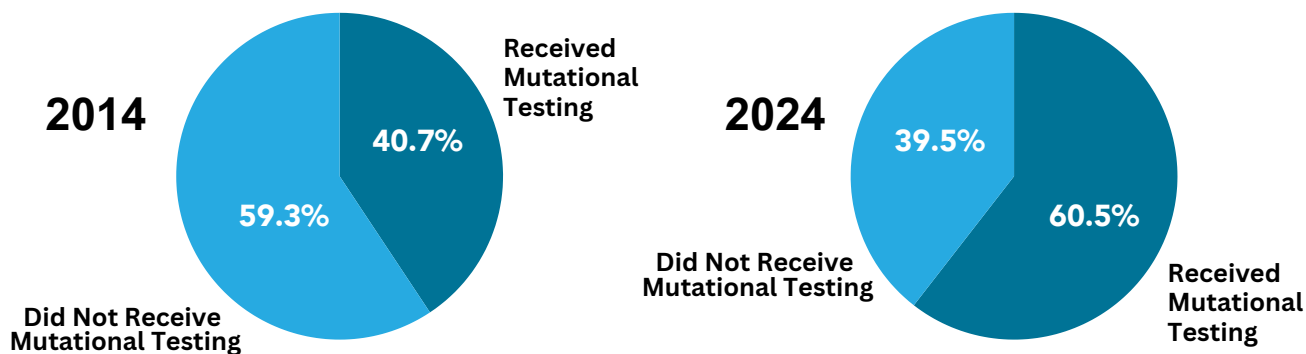
This is the heart of the LRG: a community offering daily comfort and support. We're here for each other, through every joy and heartbreak, because no one should face this journey alone.

LRG PATIENT REGISTRY

2826 Patients Enrolled

106 Countries of Birth

A Comparison of Mutational Testing Status Among Patients in Our Registry 2014 vs. 2024



There was a 20% increase in mutational testing from 2014 to 2024. The above data reflects the percent of patients in the LRG Patient Registry who had received mutational testing at the end of 2014 versus at the end of 2024.

John Poss Remembered through Memorial Fund

In March 2000, John Poss seemed to have life perfectly aligned. At 52, he had just hit a hole-in-one during a golf tournament, driving home in a shiny new silver Chrysler 300 as his prize. But just two months later, his world shifted dramatically. John was diagnosed with stage 4 GIST which had no known cure at the time. His doctors gave him less than six months to live. The diagnosis came at a time when life milestones surrounded him.



His eldest daughter had just made him a grandfather for the first time, and his youngest was about to graduate high school and head to college. John wasn't ready to miss these moments—or the countless others that might follow. Instead, he chose to fight.

John's sister, Sandra, scoured the internet for information, finding a small but connected community of GIST patients through the American Cancer Online Resources (ACOR). From this network, John learned about a clinical trial for a drug called STI-571, later named imatinib. The trial was full, but John's determination and advocacy pushed boundaries. He contacted the lead doctor and successfully secured a spot, becoming one of the first 50 patients to test the groundbreaking treatment.

That decision changed everything. Imatinib extended John's life by **24 years**—24 more years to make memories with his family, enjoy friendships, and live his passions. He met five of his grandchildren,



walked his youngest daughter down the aisle, and, true to his golfing spirit, hit even more holes-in-one. But John's story isn't just one of survival. It's one of purpose. In 2002, he became a founding member of The Life Raft Group.

As our first treasurer, he helped transform a modest \$240 budget into a global organization that now serves patients worldwide. For over two decades, John dedicated his time and expertise to ensuring others had the information, support, and hope they needed. His legacy remains one of relentless advocacy and compassion.

On July 10, 2024, at the age of 76, John passed away, leaving behind a story that continues to inspire. His advocacy work, combined with his personal determination, opened doors not just for himself but for countless others facing a GIST diagnosis.

Today, you can honor John's life by supporting the **John Poss Memorial Fund**. Every donation furthers GIST research, fuels clinical trials, and provides critical support for patients and caregivers navigating this journey. Your gift ensures that John's spirit lives on and that others will have the resources they need to fight their battles, just as he did.

Join us in carrying forward John's legacy of hope,
action, and connection.

Together, we can make a difference.

[**bit.ly/PossMemorialFund**](https://bit.ly/PossMemorialFund)



LRG Staffer Hits the Road for a GIST Ride Across America

Jerry Call, Data Analyst



Yep, that's me, packing up for the morning...1978. My second motorcycle trip across America, this one with my brother, Greg. My first trip was in 1973.

What's changed in the last 50 years?

It's time for me to find out. One of the things that I know have changed is cell phones. That grainy photo that you see from 1978 was produced by a 110 camera. So, I'll be taking a lot more and hopefully a lot better photos!



Why this trip and why now?

As I approach my 70th birthday, it's time to slow down a bit, visit family and friends, hopefully meet some new friends along the way. America is a very large, diverse and beautiful country. No matter how much you have seen, I guarantee that there's a lot more to see and experience. I'd also like to give a little bit back to The Life Raft Group (LRG) community that has been such a big and important part of my life for nearly 25 years now.

So, in addition to enjoying myself, I'm going to try to do a little fund-raising to support the LRG.

What's the LRG and why is it so important to me?

Well, if you know, you know...and if you don't, you will have to follow along to find out, for that will be another story for another day.



I invite you all to follow along, or better yet to participate in whatever way you would like. I would love to meet as many of you as I can along the way. Whether it's just to say hi, have lunch or something else. If there's something special nearby or some special restaurant that you would like to show-off, I'd love to see/try it! If you know other GIST patients nearby and want to organize a local meeting, I would love to attend.

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GIST RIDE

CONTINUED FROM PG 9

Right now, the tentative plan is to leave my house in Virginia in early May and I think this trip will be about two months. The general route will be to travel west through the southern part of the country while it's still relatively cool, to southern California. From there, traveling north probably to Seattle before turning east and going across the northern part of the country as the weather gets warmer.



I do have certain relatives and friends that I want to see, mostly along the east coast and in Colorado, where I lived for over 30 years. So, I have some spots that I know that I want to go and will spend a few days in Colorado for sure. However, I'm open to explore other places between these planned stops. The exact route and duration of the ride will, in large part, depend on you! If you want to plan an event, or just get together for a bite to eat, let me know. I can't guarantee anything, but I will try!

I have recently rejoined Facebook and will probably use that as a communications hub. Hope you can join me, in-person or virtually along the way!

Note: More info will be coming in the April newsletter & on social media. If you have questions or suggestions at this point about Jerry's trip, please reach out to Brian Morello at bmorello@liferaftgroup.org.

Scan for
information on
starting your own
fundraiser!



bit.ly/DIYfundraisers

Water of Life - Winter 2024 Event

Laura Occhiuzzi, Deputy Executive Director



Left to right: Brian Morello, Laura Occhiuzzi & Matt Lurin.

On November 19th, Brian Morello, Director of Development and I attended the annual Water of Life event hosted by Matt Lurin whose father passed away from GIST.

Over sixty people attended this whisky tasting fundraising event at Keen's Steakhouse in New York City. Funds raised from this event help support The Life Raft Group's research funding and programs that we offer to our patient community. It is always a fun and educational night getting together with this enthusiastic community of whisky aficionados. We are looking forward to the Water of Life events scheduled in 2025.

LRG Athletes Program - Surviving Strong!

Brian Morello, *Director of Development*



The LRG Athletes Program is a unique initiative designed to help individuals achieve their goals both on and off the course or field. By offering tailored resources, mentorship, and support, the program equips participants with the tools they need to excel in their chosen sport/activity while fostering leadership and wellness. More than just an athletic venture, the program empowers participants to align their passion with a deeper purpose: supporting the mission of The Life Raft Group.

Whether you're running a marathon, cycling through rugged terrain, or simply engaging in something you love, the LRG Athletes Program invites you to take your commitment to the next level. It's a chance to challenge yourself physically and mentally while making an impact in the lives of others.

A Program for Everyone

The program is inclusive, inviting not just patients and caregivers but anyone with passion and a desire to give back. By joining the **LRG Athletes**, participants become part of a larger movement that celebrates perseverance, resilience, and community spirit.

Making an Impact Through Fundraising (Optional)

One of the defining aspects of the LRG Athletes Program is its integration of fundraising. Participants are not only challenging themselves physically but also rallying support for The Life Raft Group's vital work in the GIST community. By participating, athletes raise awareness and critical funds that help further research, patient advocacy, and resources for those impacted by GIST.

Why Join?

Becoming an **LRG Athlete** means more than just competing in an event/activity. It's about:

- *Pushing your limits:* Challenge yourself to achieve new goals.
- *Finding purpose:* Combine your passion for sports with a meaningful cause.
- *Building connections:* Join a supportive network of like-minded individuals.
- *Inspiring others:* Lead by example and motivate others to pursue their own ambitions.

Join the Movement

LRG Athletes is more than just an initiative—it's a community where passion meets purpose. Together, we can push boundaries, inspire change, and make a difference in the lives of those affected by GIST. Let's run, cycle, and strive together. Your journey starts here!

Learn more - apply today - bit.ly/LRGathletes





Events 2025

IN-PERSON EVENT

MD Anderson Cancer Center, GIST Support International and The Life Raft Group are co-hosting the GIST Summit 2025 / GDOL Texas event for the GIST community this March in Houston, Texas to showcase recent developments in GIST treatments and therapies.

Meet experts from across the country and gather with fellow patients & caregivers!

AGENDA: bit.ly/SummitAgenda2025



Register:
bit.ly/GISTSummit2025-GDOL

WEBINAR



Join the National Comprehensive Cancer Network (NCCN) on February 28 for a free **NCCN Patient Webinar: Why Should I Consider a Clinical Trial?** Join trusted experts from a patient advocacy group and two leading cancer centers to learn about clinical trials. They'll explain all about clinical trials and how you can join one. *(This is general information about clinical trials and not GIST-specific)*

bit.ly/NCCNwebinar2025

Register: bit.ly/Why-Consider-Clinical-Trials

RECORDING

Recording Available:
bit.ly/SARC044TrialRec



CONNECT



A private email community for GISTers
<https://forum.gistchat.org/>

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Volunteering
with the LRG?**



**Become a
Volunteer**

Thank you our **G.E.M.** donors!

GIVE EVERY MONTH

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Even a donation of \$10 a month helps us continue to produce webinars, GDOLs, educational materials, participate in global advocacy, and contribute to research.



How to:

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