



LIFE RAFT GROUP NEWS



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



November 2025

CATCHING UP WITH THE LRG!

Over the past several months, The Life Raft Group (LRG) has been deeply engaged in strengthening connections across the GIST community. From expanding collaboration with specialists across the United States and abroad to meeting patients face-to-face through outreach and educational events, our focus has remained on building partnerships that drive better care and understanding. We welcomed community members to our New Jersey office for an Open House, continued important work around testing and patient feedback through surveys, and hosted GIST Days of Learning in Boston and Los Angeles to share the latest insights in research and treatment.

Our advocacy and awareness efforts also continued to grow, with new opportunities in Washington, D.C., and the ongoing work of our Health Equity Council. Awareness initiatives like GIST Awareness Day and Sarcoma Awareness Month united our global community to share stories, highlight patient voices, and raise visibility for rare cancers. Through every effort, our commitment to improving outcomes and ensuring that patients are seen, heard, and supported remains at the heart of all we do.

Enjoy this action-packed issue of our newsletter and be sure to check out the photo galleries of our events & meetings here:

<https://bit.ly/LRG-Photos>

In Loving Memory:

Suzanne Litzenberger, Kristin Bush, Jonathan Dennis, Diane McGauran, John Tulock, Nicholas Bush, Jeffrey Davis, Maria Baker, Martina Will, Max Jacobson, Dr. Robert Real, Bruce Galley, Raymond Letourneau, Steven Nordvall

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LIFE FEST & MORE EVENTS





ON THE ROAD WITH THE LRG

Georgia

Sara Rothschild and Carolyn Dewalt visited Atlanta to meet with healthcare providers and raise awareness about GIST and The Life Raft Group's mission. They connected with teams at Emory Winship Cancer Institute, Georgia Cancer Specialists, Northwest Georgia Oncology Centers at Wellstar, City of Hope, and Piedmont Cancer Institute.

A highlight of the trip was a large, inspiring gathering of GIST patients and loved ones that brought together many members of the local community for the first time.



China

The Life Raft Group was honored to participate in the first-ever #TGCT patient conference, hosted by the Chinese Organization for Rare Disorders (CORD). Our Executive Director, Sara Rothschild, and TGCT Support Program Director, Sydney Stern, joined clinicians, researchers, and advocates from around the world to share insights on patient education, support, and advocacy.

It was inspiring to exchange ideas with CORD and discuss how our TGCT Support model can help guide the creation of similar programs for TGCT patients in China. Moments like these remind us that collaboration across borders is the key to improving outcomes and ensuring that no patient faces their diagnosis alone.

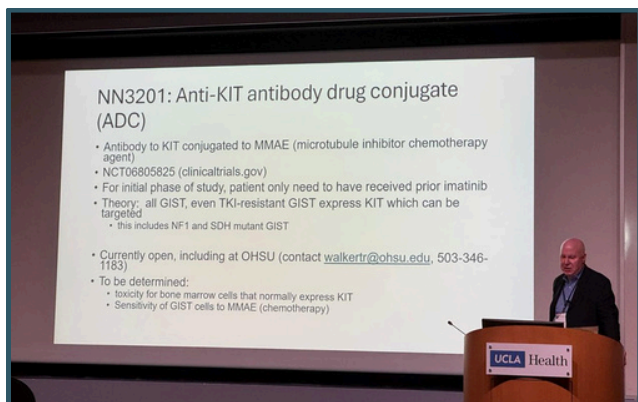
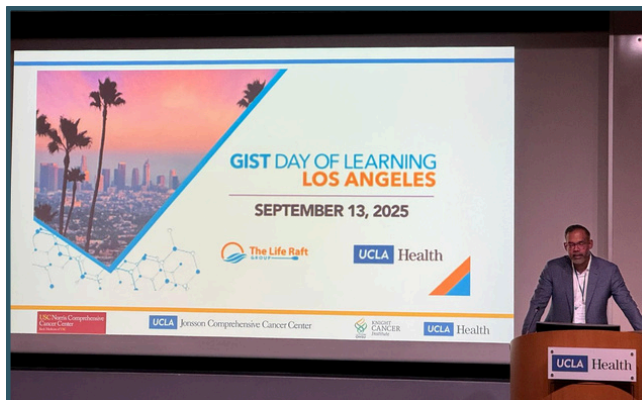




ON THE ROAD - GIST Days of Learning (GDOLs)

GIST DAY OF LEARNING LOS ANGELES

UCLA Health



**Our last two GDOLs for the year
were in LA and Boston. Read more
about these events here:**

**bit.ly/2025-Boston
bit.ly/2025-LA**

GIST DAY OF LEARNING BOSTON

Dana-Farber
Cancer Institute

Brigham Cancer Center



Presenting GIST Center of Excellence Award



GIST On The Road: Jerry Completes his cross country trip for GIST!



Jerry Call did it! He completed his cross-country motorcycle trek, visiting more than 100 patients across 18 states. Along the way, he stopped at cancer centers, hosted fundraisers, spread awareness, and raised over \$10,000 for GIST research.

Travel Timeline



**May 1
VA**

**May 12
TX**

**June 4
OR**

**June 20
IL**

**May 7
GA**

**May 23
CA**

**June 13
CO**

**June 27
NJ**



bit.ly/GISTRidePhotos



OPEN HOUSE AT THE LIFE RAFT GROUP

Welcome back to the East Coast, Jerry! We had a great time welcoming Jerry, along with GIST patients. Caregivers, advocates, and local oncologists to the LRG office!

The Open House stop during the GIST Ride tour served as a wonderful opportunity for meaningful connection and learning. It brought together LRG staff, doctors, and community members to share experiences, discuss the organization's history, and reflect on its ongoing impact.

Our Open House was a part of Jerry Call's GIST Ride tour but we wanted to share as much as possible of this event with our community. Our team loves working with GIST patients and this was a great opportunity to meet 'names' in real life so they became friends with faces. We're so grateful to Jerry & all those who came by June 27th, 2025.

View Gallery: bit.ly/LRG-OH25



This past July, the GIST community shared their stories & photos, posted GIST facts, and called for awareness of this rare disease on July 13th GIST Awareness Day (GAD) and throughout Sarcoma Awareness Month (July). Patients & caregivers also shared on our special GAD kudoboard which posed the question, "What's something unexpected that GIST has taught you – about yourself, life or people?"

View Gallery:

bit.ly/GISTAwarenessDay2025

The LRG also presented our first GIST Day of Learning for GIST Awareness Day in Spanish with presenters Dr. César Serrano, Dr. Andrew Blakely, and Berenice Carbajal-López, Director of Fundación GIST México providing information on GIST basics, treatments, and nutrition. There was also a GIST Awareness Day Fireside Chat with presenters Dr. Jason Sicklick, Dr. John Glod and Dr. Andrew Blakely who informally answered patient and caregiver questions.



SURVEY HIGHLIGHTS - Patient Perspective on Testing

Denisse Evans, Senior Director, Data Management & Research

The LRG recently conducted a **survey** to better understand the types of testing GIST patients receive, such as mutational testing, **circulating tumor DNA (ctDNA)** testing, and genetic testing with the aim of learning how patients perceive and interpret these results. The goal of the survey was to identify knowledge gaps, highlight opportunities for patient education, and better inform the GIST community about the importance of comprehensive testing. This analysis reflects responses from 143 patients residing in the United States.

Most GIST patients undergo mutational testing, but awareness of ctDNA remains limited.

Key Takeaways

- Mutational testing is common: 81% of GIST patients report receiving it, with KIT exon 11 being the most frequent mutation.
- ctDNA awareness is low but interest is high: 79% had never heard of ctDNA, yet 76% believe it is very important once explained.
- ctDNA is not for everyone: Tissue-based testing remains the gold standard, and ctDNA is still being studied; patients must meet certain criteria to benefit.
- Patient confidence is moderate to strong: 42% of patients rated themselves a 4 out of 5 in understanding their mutational testing results.

Most respondents were LRG members (96%), and 72% are also enrolled in the LRG Patient Registry. The majority were women (64%), white, non-Hispanic (95%), and aged 65 or older (60%). At diagnosis, 64% reported a single tumor compared with 25% who were metastatic, and most patients currently reported being “no evidence of disease (NED)”.

Testing was widely reported, with 81% of participants receiving mutational testing. The most common mutation was KIT exon 11 (65%), followed by KIT exon 9 (12%), PDGFRA exon 18 (11%), and SDH-deficient GIST (9%). Awareness of ctDNA testing, however, was strikingly low—79% of patients had not heard of it prior to the survey and only 13% of those who received testing reported actually receiving ctDNA. Yet despite this lack of familiarity, 76% of patients said they believe ctDNA is a very important test.

ctDNA testing, often called a “liquid biopsy,” analyzes tumor DNA fragments circulating in the bloodstream. It offers the promise of non-invasive monitoring and may one day provide new insights into tumor mutations, treatment response, and recurrence. However, it is important to note that ctDNA is not appropriate for every patient. At this time, tissue-based testing remains the gold standard for diagnosing and guiding treatment in GIST. ctDNA is still being studied in research and clinical settings, and patients must meet certain criteria, such as having sufficient detectable tumor DNA, for the test to provide useful results.

When asked about their confidence in understanding mutational testing results, patients most often rated themselves a 4 on a 5-point scale (42%), suggesting strong but not complete confidence.

This survey highlights both the progress and the challenges in educating patients about available testing. While most GIST patients are receiving mutational testing and feel reasonably confident in understanding their results, awareness of ctDNA testing remains limited despite its promise. These findings reinforce the importance of continued patient education, advocacy, and access to cutting-edge tools, while reminding us that tissue-based testing remains the cornerstone of care today.

Why ctDNA Matters For GIST:

- Can sometimes identify tumor mutations without surgery
- May offer a way to monitor treatment response or recurrence
- Provides promising opportunities for more personalized care

Important To Know:

ctDNA testing is not for everyone. At this time, tissue-based testing remains the standard for GIST. ctDNA is still being studied, and only certain patients meet the criteria for it to be useful.

Life Raft Research Award Recipients of 2025

Summer Splash Match Funds Go to Groundbreaking Work in GIST Research

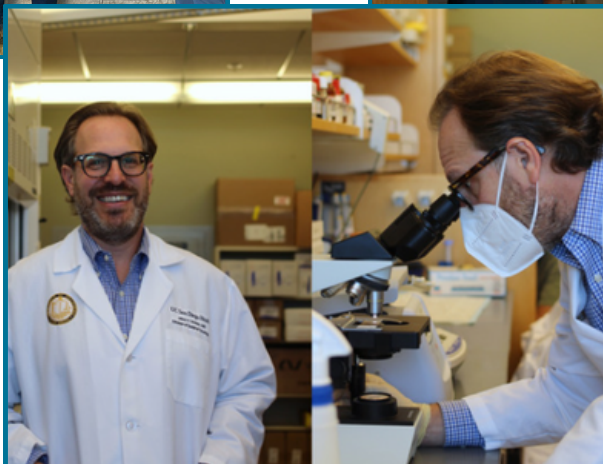
This summer, The Life Raft Group held a Summer Splash Match to raise funds to directly support groundbreaking GIST research. Our generous community contributed \$30,000 bringing our total with the match to \$60,000 for research.

Three exceptional investigators making significant strides in GIST research were awarded these funds:

- Dr. Inga-Marie Schaefer of Brigham and Women's Hospital for her project, "Exploiting Cell Cycle Perturbation in GIST for Therapeutic Targeting."
- Dr. Matthew Hemming of UMass Chan Medical School for his project, "Identification of novel therapeutic strategies for succinate dehydrogenase (SDH)-deficient gastrointestinal stromal tumor." for his innovative work advancing our understanding of GIST biology and treatment strategies.
- Dr. Jason Sicklick of UCSD Moores Cancer Center for his project, "Translating RNAseq signatures to treatment of GIST." focused on developing new treatment options for SDH-deficient GIST.

Each of these projects represents meaningful progress toward improving outcomes and offering hope for patients living with GIST. The Life Raft Group is proud to stand behind these talented researchers and the community of supporters who made these awards possible.

Together, we continue to drive research forward, one discovery at a time.





Continuing the Legacy of a Beloved Member



Rebecca Pauley
Program Director



LRG
Health Equity Council

The Life Raft Group's Health Equity Council (HEC) meets bi-weekly to advance our mission of ensuring that every patient has equitable access to the care and information they need. Made up of dedicated patient advocates, we are working to build strategies that strengthen collaboration with medical professionals and the patient community. Together, the council focuses on ways to close gaps in care and empower patients.

This mission has taken on deeper meaning as we honor the memory of beloved Council member Martina, whose passion for health equity inspired us all. As we mourn her loss, we remain determined to carry her legacy forward by ensuring that no patient is left behind.

At our most recent meeting, team member Rob (a veteran) shared encouraging news about his progress in connecting with leaders at the Veteran's Association (VA). He is getting closer to a key decision-maker and working toward securing a meeting that could open the door to new opportunities for collaboration. By building these relationships, we hope to help the VA better support veterans impacted by sarcoma.

The Council also focused on outreach over the past few months to smaller cancer centers in the Southeast U.S., where many patients still lack access to the life-saving resources and information provided by The Life Raft Group. To make this work more effective, HEC developed a tracking system to organize centers we have already contacted and those we plan to reach out to. Team member Carolina has been tasked with locating cancer centers with large populations of Spanish speakers to provide bilingual outreach and educational materials. Through the work of the Health Equity Council, The Life Raft Group is committed to building strong, lasting partnerships with these centers to ensure every patient has equitable access to the care and information they need.

To keep up the momentum, the Council is also exploring ways to expand its team with additional volunteers who can strengthen our outreach and engagement efforts. If you are interested in joining the Health Equity Council, please email: rpauley@liferaftgroup.org

Discussion groups for
GIST patients & caregivers:



reddit
r/GIST_Survivor



GISTCHAT

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

LOOKING FOR SUPPORT?

The LRG has an online support group for patients and one for caregivers. There are also regional groups that meet regularly. For more info email us at liferaft@liferaftgroup.org.

SDH SUPPORT GROUP

Connect with fellow SDH patients online to share experiences, support and stories. For more info contact Becky at bowens@liferaftgroup.org



GISTMENTOR

We also have mentors for patient and caregivers. Read more info on our GIST Mentor Program here: bit.ly/GIST-MentorProgram

Annual SPAGN Conference in DC



Sr. Director of Marketing and Communications Director Carol Tordella & Engagement Specialist Carolyn Dewalt represented the LRG at the 15th annual SPAGN (Sarcoma Patient Advocacy Global Network) Conference this past spring. This was the first-ever SPAGN conference in the US, where 120+ patient advocates, experts, and partners from nearly 30 countries came together to connect, learn, and collaborate.

The conference featured plenary sessions, disease-specific tracks, and interactive workshops exploring key themes such as international collaboration, patient-partnered research, clinical trial accessibility, the power of patient data, and disparities in sarcoma care.

The event also featured special sessions on soft tissue and bone sarcomas, GIST, and Desmoid tumors, along with a celebration of outstanding achievements.



LRG Director Emeritus Norman Scherzer received a lifetime achievement award for his 20+ years of patient advocacy work. (Carol & Carolyn accepted on his behalf and SPAGN Board Chair Markus Wartenburg praised Norman's work.)



Norman accepted his award in person at our office a few days later.

Sarcoma Community Advocacy Day

The LRG participated in Sarcoma Community Advocacy Day (sponsored by the Sarcoma Foundation of America) in Washington, D.C. on July 17th, joining over 30 patient advocates to represent the needs of patients, caregivers, and families affected by sarcoma. Through meetings with legislators, patient advocates highlighted the importance of research, access to treatments, and support for the community.

Being part of events like this is crucial for the GIST community and other rare sarcoma communities. Advocates serve as the voice for patients who may not otherwise have the opportunity to influence policy decisions, helping to secure funding, improve treatment access, and expand resources for research and patient support. The experience was a valuable opportunity to connect with advocates from other rare cancer communities, all sharing the same goal of advancing research, improving treatment access, and supporting patients and families.



New Wellness & Positivity Board

Initiated by GIST advocate & board member, John Abrams, the LRG has created a new venue for GISTers to share their journey and encourage each other to move, create, and make this journey of survival an amazing experience. You are invited to join this group as a viewer or participant - share what keeps you motivated to live the best life you can!

Health, Wellness & Positivity Board for GISTers

A supportive online space for GISTers to connect, share their health and wellness wins, and spread encouragement and positivity. Feel free to share your fitness journey, your reflections, your art or any activity that makes you feel positive living with GIST.

From The Life Raft Group



Doing what I love to do makes me happy. I have always made time to do the things I enjoy the most, especially time spent with my family (3 children, 6 grandchildren). I have been a GISTer since 1997 so, of course, I feel extremely fortunate. Good science, medicine, and the Life Raft Group have had a huge impact on my life.

I'm a very active person (even at age 76). I love playing golf as it keeps me outside (I like it better when I play well 😊). I also box (training only) once a week.

I built a small garden several years ago and replant annuals every May. People ask me what flowers I plant. My response is "red, yellow, white, etc". I love coming downstairs in the morning, looking out my backyard and seeing the colors. It starts my day off with a smile.



From John Abrams

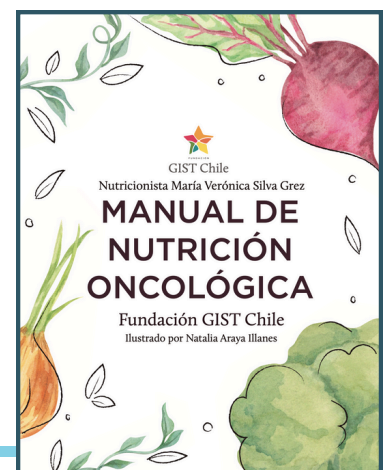
If you are interested in viewing/participating in this board please visit:
<https://liferaftgroup.kudoboard.com/boards/W3idyT8o/Positivity>



Congratulations to advocacy partner **Fundación GIST Chile** on their 11th anniversary! We are extremely proud of all that Piga Fernández and the team have accomplished for cancer patients in Chile!

They have helped spearhead new cancer laws in their country as well as being a part of **Alianza GIST** - an alliance of Latin American countries plus Spain, working together to improve the survival of GIST patients.

This summer **GIST Chile** produced a well-received cookbook for cancer patients. Lee en español aquí:
bit.ly/ManualDeNutricionOncologica





Heather Bliss Turns Her GIST Journey into Action



Heather Bliss exemplifies resilience and dedication, both as an athlete and as a patient advocate for those affected by GIST. Diagnosed with GIST in 2023, Heather faced her diagnosis with unwavering strength, transforming her journey into a platform for raising awareness and supporting research.

As an active participant in the LRG Athletes Program, Heather has engaged in various fundraising events, including marathons and endurance challenges, to support GIST research. In November, she'll tackle her first HYROX, a fitness race that combines running with CrossFit-style functional workouts.

Support Heather's fight against GIST:

bit.ly/LRG-A-HBliss



Rachel LoCurto Takes a Leap for GIST Research

Rachel LoCurto, Senior Vice President of The Life Raft Group, took her advocacy to new heights. On October 15, Rachel participated in Pledge the Edge in Atlantic City, NJ, rappelling down a building to raise funds and awareness for GIST research.

As an LRG Athletes, Rachel's raised \$3,500 to support ongoing research and patient-driven initiatives. Her adventurous spirit and dedication to the GIST community continue to inspire those around her.



Check out Rachel's Kudoboard:

bit.ly/RachelKudo





Natalie Power Conquers 29 Miles for GIST Research

Natalie took on a mountain to raise awareness & funds for the GIST community. With your encouragement, she raised over \$11K and completed a marathon hike of 29 miles, 7,000 vertical feet of elevation in the Wasatch Range near Park City, Utah.

Natalie was diagnosed with GIST in 2023, after finding multiple tumors on her gastrointestinal tract with no warning signs. Facing surgery and ongoing treatment, she didn't let it stop her. With determination, grit, and her amazing crew by her side, Natalie proved anything's possible.

"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."

-Natalie



Evelyn Swam to Honor Her Grandmother's Fight with GIST



At just 13 years old, Evelyn Chen is already making waves—literally and figuratively. This fall, Evelyn joined the Swim Across America 2025 Dallas Open Water Swim at Lake Ray Hubbard, taking on the 2-mile distance in memory of her grandmother, Anna Chen. Evelyn's grandmother passed away in 2021 from GIST.

Through her efforts, Evelyn not only swam in her grandmother's honor but also raised funds and awareness for the GIST community. Her dedication at such a young age is a reminder that compassion and courage can make a powerful impact, no matter your age.

"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."

-Evelyn



LRG Staffer Goes the Distance for the GIST Community

Toni ran a marathon not just for the miles—but for the lives behind every step.

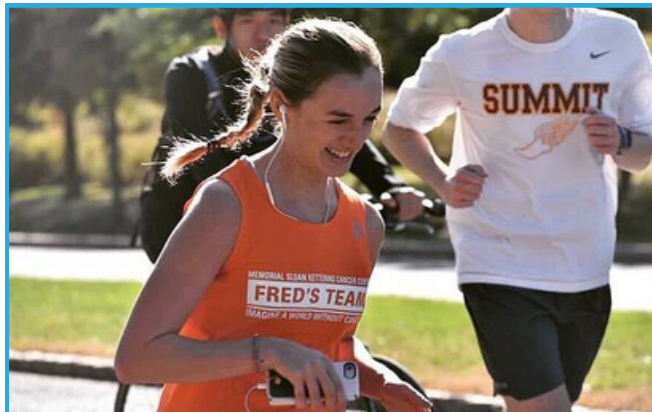
On June 21st, she took on the ZIP code 07762 marathon in Rochelle Park, New Jersey, to raise funds and awareness for GIST cancer research through the Life Raft Group (LRG). Before joining the Life Raft Group as a staff member, Toni had never heard of GIST—a rare and often overlooked form of cancer. But the moment she stepped into the role, her world changed. She didn't just learn about mutations and treatment protocols—she was introduced to the powerful, often heartbreaking human stories behind each diagnosis.

Some of the most profound moments in her work came during patient calls. Those conversations opened her eyes and reshaped her heart. She listened to the anxiety of waiting for test results, the uncertainty of rare mutations, and the quiet strength it takes to face each day with courage. The resilience of the GIST community inspired her daily—and, during the race, fueled every mile she ran.



If you have interest/questions about the LRG Athletes Program, reach out to Brian Morello: bmorello@lifteraftgroup.org

Brian Morello
Director, Development



Running had always been Toni's outlet—a way to manage anxiety, process emotions, and find clarity. Over the years, she had completed three marathons, including one with Fred's Team at Memorial Sloan Kettering, raising over \$3,000 for rare cancer research. But this race was different. This one was deeply personal.

Every mile was for the GIST community. She ran for the patients she had met, the stories she carried, and the hope that, together, we can push research forward and ensure no one faces this disease alone. With every stride, she honored those battles. With every step, she advocated for change.

No matter how hard the run became, Toni kept going—for them. Her journey continues to inspire others to donate to The Life Raft Group and join their mission to support patients with gastrointestinal stromal tumors through education, advocacy, and research. Support like this from the community helps bring hope to those who need it most.

Share your journey:
bit.ly/GIST-Strong

Welcome to our Newest Board Member!

Rob Taylor has guided patients, shaped programs, and helped strengthen the community. Drawing from his own patient experience, he has been instrumental in guiding programs, mentoring others, & advancing awareness and support for those living with GIST.



"We have a lot of chaos in our life. We have normal chaos just with dealing with life in general and then this diagnosis gives us extreme chaos. The LRG calms down the chaos and gives us not only hope but saves our lives. It gives us hope, and it creates a normalcy in the chaos that we're experiencing. The LRG helped me. They put the work in to help me and they didn't have to do that."

- Rob Taylor

Congratulations to Christina Ochs on Her White Coat Ceremony!

A proud Villanova University alum, Christina spent the past year on our Data Management & Research Team before applying to medical school. She continues to support GIST patients part-time while pursuing her dream of becoming a physician. We are incredibly proud of Christina and excited to follow her journey.

Christina shared:

"I am deeply grateful for the opportunity to have worked at The Life Raft Group as a Data Management and Research Manager over the past year. As I move into the next chapter of pursuing my dream of becoming a physician, I will carry with me the stories and strength of every GIST patient. I have grown tremendously through the guidance of patients, colleagues, and the physicians dedicated to advancing research toward a cure. From Denisse, I learned how to recognize patterns and frame research questions; from Jerry, I gained valuable skills in data analysis; and from Toni, I witnessed the importance of building meaningful relationships within the patient community. Thank you to everyone at The Life Raft Group for your support—I will take these lessons with me as I begin my journey in medicine."



A Memorable Evening at Water of Life

What an Unforgettable Night of Action & Generosity!

Brian Morello
Director, Development



On June 25th & 26th, we gathered for the inaugural Water of Life whisky speed tasting event, and we couldn't be more thankful for everyone who joined us. Hosted in support of The Life Raft Group and co-led by the ever-passionate Dr. Matthew Lurin, the evening was a true celebration of community, craftsmanship, and compassion.

From rare pours to heartfelt conversations, the event was filled with warmth and purpose. Attendees sampled unique whiskies from some of the world's most renowned brands while learning how their support fuels critical research, advocacy, and resources for patients living with GIST — a rare and often overlooked cancer.

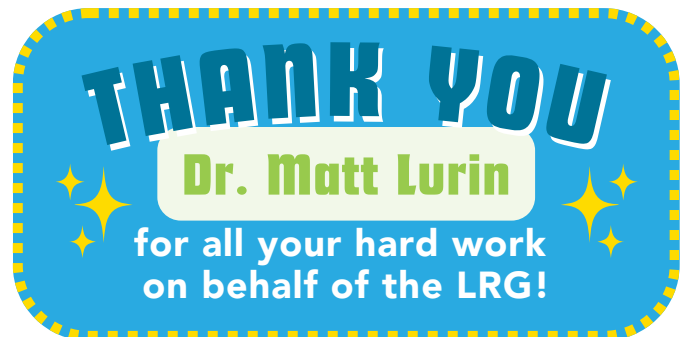
Our Ultra VIP guests kicked off this two-night event by attending a special dinner at the Flatiron Room in the heart of NYC coupled with some of the most popular whisky.



The evening was capped off at the Carnegie Club where guests enjoyed some additional pours paired with their favorite cigar.

Home Studios offered the perfect setting for day two! On the following night, our Ultra VIP and VIP ticket holders took part in an unforgettable whisky experience featuring two whisky masterclasses followed by 11 tables of whisky speed tasting, while our Standard ticket holders participated in the speed tasting portion of the event.

Whether you were a seasoned connoisseur or new to the dram, guests left with new favorites, new friends, and a deepened commitment to making a difference!



View Full Gallery:
bit.ly/WOLphotos2025

Remembering Martina Will

Laura Occhiuzzi
Deputy Executive Director

With heavy hearts, we remember and celebrate the life of a remarkable woman, Martina Will. Martina embodied strength, compassion, and an unshakable love for her family and community. She was, first and always, a devoted mother. Her children were the light of her life, and everything she did, every challenge she faced, was met with the fierce love only a mother can give. Her legacy lives on in their hearts, their laughter, and the values she so gracefully instilled in them.

Even during her own battle with GIST, she never stopped giving. She served on our Health Equity Council, determined to make the journey easier for others facing the same fight.

She fought her illness with unwavering courage, resilience, and grace. Martina was determined to visit her sister in Hawaii despite her weakened state. She sent us a picture of the ocean, peaceful and serene- Martina was a fighter until the end.

Though she is no longer with us in body, her spirit lives on in the lives she touched, the family she loved, and the causes she championed. We honor her not only for how she passed, but for how she lived, with purpose, kindness, and heart.

She is deeply loved. She will be forever missed.



"There's a lot 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 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 who I don't think any of them even have any skin in the game. I don't think any of them are patients, to my knowledge, but they are incredibly knowledgeable, and they really fight for us."

-Martina Will

Join us at LIFE FEST 2026

REGISTER

Enjoy a weekend of education, connection, & hope at Life Fest!

This biennial Life Raft Group event is a gathering of patients, caregivers, and the medical and scientific community, all coming together for a deeply meaningful experience. At its heart, it's about patients & caregivers building connections, and finding strength in one another as we unite in hope.

What Does Life Fest Offer?



EDUCATIONAL RESOURCES

GIST patients face a rare and complex disease, with subtypes that respond differently to treatment. Life Fest provides trusted information to help patients understand their diagnosis and stay informed as science continues to evolve.



CURRENT RESEARCH

Workshops give patients clear insight into the latest research, treatment options, and side effect management. They leave with knowledge that empowers them, and with hope knowing scientists are working toward a cure.



COMMUNITY SUPPORT

Joining with fellow patients and caregivers from around the world builds a sense of belonging that is powerful and healing. At Life Fest 2026, shared stories and connections remind every attendee they are not facing this journey alone.



EMPOWERMENT & HOPE

Life Fest offers more than information—it renews strength and purpose. Patients and caregivers gain practical tools, deeper understanding, and renewed confidence in the progress being made toward better treatments and the hope of a cure.



Hotel Details

Loews Nashville Hotel at Vanderbilt Plaza

There is a block of hotel rooms for guests attending Life Fest. This special group rate is available until June 19, 2026.

(All conference sessions will be held at this hotel.)

Airline discounts and parking information are available on the registration page. Agenda TBD.

Questions about Life Fest?

Please reach out to Brian Morello, Director of Development at bmorello@liferaftgroup.org

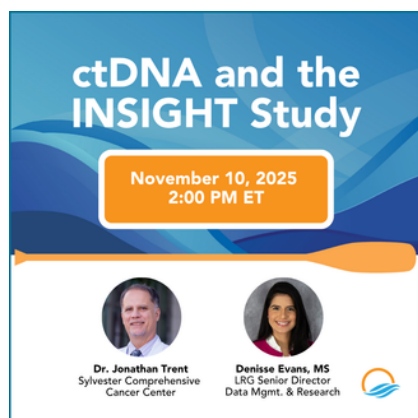


Events 2025

VISIT OUR EVENT PAGE FOR THESE EVENTS:

bit.ly/LRGEEvents2025

WEBINAR



NOVEMBER 10

FUNDRAISING EVENTS

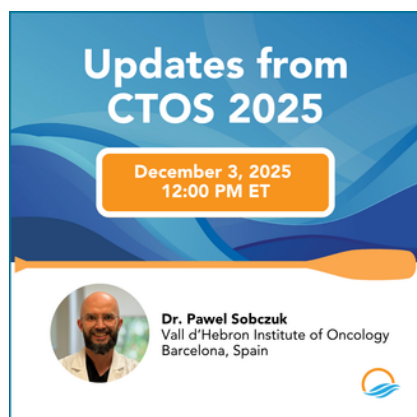


NOVEMBER 13



NOVEMBER 20

WEBINAR

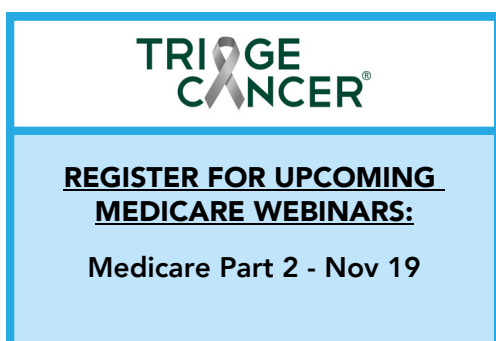


DECEMBER 3



JULY 10-12, 2026

IN-PERSON
WEEKEND-LONG
EVENT



Watch the latest videos
on treatments, trials,
side effects & nutrition.

Check out all the photo galleries for the latest LRG events!



Visit all our Kudoboard: bit.ly/LRG-Photos

Interested in Volunteering?



Want to Donate?





GIVE EVERY MONTH TO SUPPORT GIST RESEARCH

THANK YOU TO OUR GEM DONORS!

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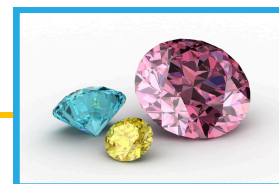
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