SPECIAL LIFE FEST/GAD NEWSLETTER












Navigating Rare Together

Empowering Patients Living with GIST

DONATE

The Life Raft Group is committed to enhancing the survival and quality of life for people living with Gastrointestinal Stromal Tumor (GIST), and other rare diseases, through patient-powered research, education and empowerment, and global advocacy efforts. Our vision is to empower a future fueled by data, guiding our journey toward cures for rare diseases.

Summer was a busy time for The Life Raft Group. In addition to our normal, everyday work with patients & caregivers, we were also preparing for Life Fest behind the scenes. This is an enormous task which is worth every moment of time & energy we (the staff) and our volunteers pour into it.

In this issue of our newsletter, you can hear about different aspects of our event in Nashville from Sara Rothschild, our Executive Director, and Denisse Evans & Ian Hill of our Data Management & Research Team who shared an exciting update on our new Patient Registry. In addition, we're releasing the videos & PDFs of the event today and those can be seen on our YouTube channel.

This milestone shows why research into rare diseases matters. It also highlights the power of patient registries. Every patient who shares their experience helps us better understand rare cancers and move research forward.

One of the best parts of this community is getting to share your stories. If you have a milestone, a personal update, photos from an event, or a story that could inspire others, please send them to us. We love highlighting the many voices that make our community so special. Email Carol Tordella at ctordella@liferaftgroup.org

LIFE FEST 2026 PRESENTATIONS

Featured Articles:

Reflections from Life Fest

by Sara Rothschild, Executive Director



Every time we hold a Life Fest meeting, I say, “This is the best Life Fest we’ve ever had.” This time, I really, really mean it.

There was something different about this year’s gathering. Maybe it was the energy in the room. Maybe it was the way patients, loved ones, and physicians moved so naturally between conversations. Or maybe it was the feeling that, for one weekend, we weren’t just talking about what it means to navigate a rare disease—we were navigating it together.

Friday evening set the tone. I had the chance to greet old friends and welcome new faces, and it was wonderful to see physicians mingling with patients in such a relaxed, social setting. These moments matter. They break down the distance that can sometimes exist between the person sitting in the exam room and the person sitting across the desk.

During Saturday morning’s kickoff, our Board Chair, Gary Glasser, offered an analogy that stayed with me. Inspired by the FIFA World Cup and the power of the Norway fans rowing together in unison, that is The Life Raft Group. We are all in the same life raft, and we move forward when we row together.

It isn’t just patients and their loved ones who are in that raft.

If you had the opportunity to engage with a sarcoma expert (and I hope all of you reading this have), you know that many of these physicians bring an extraordinary level of passion and commitment to this community. They don’t simply treat GIST or sarcoma. They care deeply about the people living with these diseases. They want to understand what patients are experiencing, what they need, and where the system is falling short.

They want to row with us.

You could feel that throughout the weekend. During the Q&A sessions, one patient would ask a question, one physician would respond, and another would build on that answer. The conversation became bigger than any one person or specialty. It was a powerful reminder of why communication and multidisciplinary care matter so much in rare disease. No single person has every answer. But when we bring the right people together, we can get much closer to finding them.



We also heard about new and promising treatments on the horizon. That matters. For a community that has spent decades fighting for more options, scientific progress is more than an abstract concept—it is possibility. It means there are new paths forward, new questions to ask, and, increasingly, more choices to consider.

Life Fest is not only about treatments.

Patients spoke honestly about the importance of communication with their

managing a chronic and often unpredictable disease, and the toll that cancer can take not only on patients but on the people who love them. Those conversations are just as important as the scientific ones. A treatment plan exists in the context of a person's life. We cannot separate the disease from the human being living with it.

Several physicians told us they had never attended a meeting quite like Life Fest and that the conversations with patients stayed with them, not just as physicians, but on a deeply human level.

That is exactly why we do this.

The Life Raft Group's role in this community is unique. We bring people together who may otherwise never have the opportunity to sit in the same room—to connect patients and loved ones with the clinicians and researchers who are working to change the future of these diseases. We create a place where questions can be asked openly, experiences can be shared honestly, and knowledge can move in both directions.

To everyone who attended: thank you for showing up, asking questions, sharing your experiences, and helping move this community forward.

To those who were on the fence about attending in person, I encourage you to watch the recordings. You will learn a lot. I also want to say this: you will not get everything from a video.

There is something intangible about being in that room. It is the hug from someone who understands without needing an explanation. It is the physician who stays after a session to answer one more question. It is hearing another patient say something you thought only you were experiencing. It is the energy that builds when hundreds of people who understand the weight of this disease come together and realize they are not carrying it alone.



You can watch a presentation later. You can read the slides. You can catch up on the science.

But you cannot replicate that feeling.

Life Fest reminds us that we are not rowing alone. And when we row together—with patients, loved ones, and physicians pulling in the same direction—we can move this community somewhere new.

That is The Life Raft Group's role: to bring the right people into the raft, give them the tools and information to keep moving forward, and make sure no one has to row alone.

LIFE FEST 2026 NASHVILLE

Thank You to Our Sponsors:

GSK · cogent BIOSCIENCES · deciphera a member of ONO PHARMA · blueprint MEDICINES a sanofi company · SHORLA ONCOLOGY THE HEART OF INNOVATION · ADI bioscience · VANDERBILT-INGRAM CANCER CENTER · Cancer UT MD Anderson · SYLVESTER COMPREHENSIVE CANCER CENTER UNIVERSITY OF MIAMI HEALTH SYSTEM · The James The Ohio State University COMPREHENSIVE CANCER CENTER

GIST Awareness Day – Celebrating Life

by Carol Tordella, Sr. Dr., Marketing & Communications

GIST Awareness Day (GAD) 2026 brought together patients, caregivers, advocacy groups, researchers, healthcare organizations and industry from around the world. Across social media, people shared personal stories, GIST education, treatment and research updates, and messages about the importance of getting the right diagnosis and finding GIST specialists. A strong theme throughout the day was making sure people affected by GIST know they are not alone.

GIST Awareness messaging throughout July for Sarcoma Awareness Month, joining thousands of patients, caregivers, advocates, organizations, and medical professions working to raise awareness for sarcomas – rare cancers which affect over 13k new patients each year and has over 70 types of soft tissue sarcoma. That's 1 percent of all cancers diagnosed each year in the US (according to the NIH.) We also celebrated Wear Yellow Wednesday on July 8th. All in all, the LRG posted over 37 awareness posts for the month of July garnering over 40k views across our social media channels.



Members of our GIST community came together to encourage others by sharing their stories on our GAD kudoboard which asked GISTer celebrate the moments that matter and share your milestones, victories, and experiences living with GIST.

View the 2026 kudoboard, be encouraged by others and share your story. Share this board with others to raise awareness for GIST.

2026 GIST AWARENESS DAY STORIES



The NEW LRG Patient Registry Presented at Life Fest

by LRG Staff

The Life Raft Group's Denisse Evans, Sr. Director of Data Management & Research, and Ian Hill, Data & Registry Systems Analyst, of discussed the new features of the new, updated Patient Registry that launched in July 2026 at Life Fest 2026 in Nashville. A Q&A followed the session. View the presentation below.

If you have questions about the new registry features or have questions, please reach out to patientregistrydepartment@liferaftgroup.org



Sarcoma Patients Walk for Hope in Nashville!

by Egny Mendoza, Communications Associate/Graphic Designer

One of the most meaningful traditions of Life Fest is coming together as a community to celebrate hope, resilience, and strength. On the final morning of Life Fest 2026, attendees gathered in Nashville, Tennessee, for a Walk for Hope, bringing together patients, caregivers, families, advocates, healthcare professionals, researchers, and supporters in a shared celebration of strength and solidarity.

This year marked an exciting new chapter. While previous Life Fests featured the biennial GIST Do It Walk, the 2026 event introduced a joint Walk for Hope, uniting the GIST and liposarcoma communities for the very first time. It was a powerful reminder that, although each rare disease presents unique challenges, the need for connection, support, research, and hope is something both communities share.

More than 100 participants gathered on Sunday morning to walk through the beautiful Vanderbilt University campus. With clear skies and comfortable weather setting the stage, the walk became more than a chance to enjoy the morning, it was an opportunity to slow down, connect beyond the conference rooms, and simply be together. Conversations flowed naturally, new friendships were formed, and familiar faces reunited, all while walking side by side with people who truly understand the rare cancer journey.

What made the Walk for Hope so special wasn't the distance we walked, but what each step represented. Every participant had their own reason for being there. Some walked in celebration of survivorship, others in honor of loved ones, and many walked with hope for continued research and better treatments. No matter the reason, everyone shared the same goal: to support one another and remind each other that no one has to face sarcoma alone.

The event not only debuted a new tradition for these communities but also raised nearly 10K in funds to support rare cancer research.



View Walk for Hope Gallery



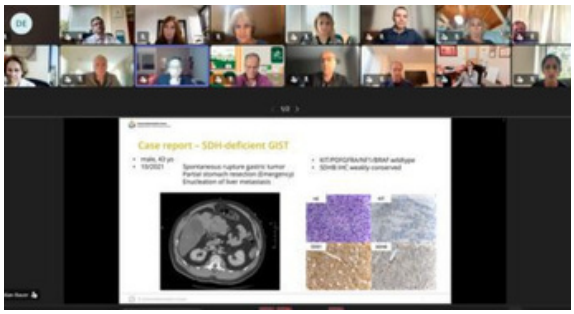
Pediatric & SDH-Deficient GIST Consortium Meets

by Denisse Evans, Sr. Dr., Data Management & Research

Driving Progress for SDH-Deficient GIST Research

Most GIST tumors are driven by mutations in the KIT or PDGFRA genes, and those cases usually respond well to targeted therapy like imatinib. SDH-deficient GIST is a rarer, distinct subtype: it lacks mutations in KIT or PDGFRA and instead loses function of an enzyme called succinate dehydrogenase, or SDH, often due to a mutation in one of the SDH genes that can sometimes run in families. This subtype tends to show up in younger patients, usually grows in the stomach, and does not respond to the standard GIST drugs the same way, which is why it needs its own dedicated research and its own treatment strategies.

Rare cancers rarely get the resources they deserve nor is there an urgency to expedite research and funding, which is exactly why The Life Raft Group created the SDH Consortium. This group brings together global leading researchers, oncologists, and patient advocates who focus on SDH-deficient tumors, including SDH-deficient GIST and paraganglioma/pheochromocytoma (PPGL), as well as bring external experts whose expertise can be applied to the SDH community so that discoveries move out of the lab and into real treatment options as quickly as possible. The Consortium is one of the clearest examples of The Life Raft Group's mission in action: connecting science and the patient community around a disease that too often gets overlooked.



At the July 22 meeting, that mission showed up in every presentation. Dr. Alice Soragni, whose lab is now based at the University of Colorado Anschutz Medical Campus, shared how her team is growing organoids, small lab-made replicas of patients' own tumors, to test drug responses faster and more affordably than ever before, including a promising early signal for a repurposed drug in PPGL. Dr. Hussam Alkaissi, from the National Institute of Child Health and Human Development, introduced a new, free platform called PPGLomics that gives researchers and doctors a much clearer window into the genetics of these rare tumors, with plans already underway to expand it to SDH-deficient GIST at The Life Raft Group's request. Dr. Suzanne George, of Dana-Farber Cancer Institute, gave an encouraging update on the pemigatinib clinical trial for SDH-deficient GIST, now open at her institution and expanding to more sites across the country. Dr. Sebastian Bauer, of the West German Cancer Center at University Hospital Essen, shared a case study of an SDH-deficient GIST patient, whose cancer had stopped responding to every standard treatment, until deeper genetic testing uncovered a FGFR mutation that led his team to consider pemigatinib, which has demonstrated promise for the case presented . This highlighted the importance of additional testing and how to tackle resistance mutations.

Meetings like the SDH Consortium are possible because The Life Raft Group brings together investigators and experts who are advancing the field through laboratory discoveries, innovative data tools, clinical trials, and other research initiatives. By sharing knowledge, fostering collaboration, and connecting complementary areas of expertise, these meetings help inform one another's work, accelerate progress, and move us closer to a cure.

If you are a patient or a caregiver with SDH-deficient GIST and would like to learn more about this consortium, please contact us at liferaft@liferaftgroup.org

You can also support SDH research by donating here.

Water of Life 2026 Recap

by Brianna Enciso, Development Manager

On June 24 and 25, we gathered for Water of Life whisky tasting event, and we couldn't be more grateful to everyone who joined us. Hosted in support of The Life Raft Group and co-led by the ever-passionate Dr. Matthew Lurin, the event was a true celebration of community, craftsmanship, and compassion.



This year marked an exciting new chapter, with both evenings hosted at Home Studios, providing the perfect backdrop for two unforgettable experiences. Guests sampled exceptional whiskies from some of the world's most renowned distilleries while learning how their support fuels critical research, advocacy, and patient resources for those living with GIST—a rare and often-overlooked cancer.

The festivities began on June 24 with our Ultra VIP Experience. Guests enjoyed several rare and exclusive pours in a relaxed and welcoming atmosphere. It was an intimate evening that set the stage for an unforgettable event.



Dr. Matt Lurin

On June 25, our Ultra VIP guests returned for two engaging whisky masterclasses before being joined by our VIP and Standard ticket holders for nine whisky speed tasting tables. Guests had the opportunity to explore an outstanding selection of whiskies from around the world while learning from industry experts and fellow enthusiasts. Whether seasoned collectors or newcomers to whisky, attendees left with new favorites, new friendships, and a deeper appreciation for the incredible whisky community.

One of the evening's highlights was our live auction, expertly led by Ian Hill. Guests enthusiastically bid on unique whisky experiences and collectibles, while one lucky winner took home an extraordinary tasting collection featuring a variety of rare samples—from vintage Blackadder releases to a Port Ellen sample distilled in 1979 and drawn directly from the cask just one month before the event. The collection also included exclusive samples from Artisanal Spirits' single casks that are still aging and available for future purchase.

The excitement continued with our raffle on Thursday evening, giving attendees even more opportunities to support The Life Raft Group while taking home fantastic whisky-related prizes. The generosity shown through the auction, raffle, and ticket sales played an important role in advancing our mission.

Most importantly, Water of Life brought together a remarkable community united by generosity and a shared commitment to improving the lives of GIST patients around the world. From meaningful conversations to exceptional tastings, the event demonstrated the power of coming together for a cause that truly matters.

A heartfelt thank you to our volunteers, donors, whisky partners, and every guest who attended. Your generosity and enthusiasm made Water of Life event an incredible success.



We look forward to raising another glass with you at WOLF on November 19!

VIEW PHOTO GALLERY

Patient Stories

A Tribute to Teena Petersohn

by LRG Staff



At Life Fest 2026, we had the opportunity to recognize and celebrate Teena Petersohn for her years of dedication to The Life Raft Group and the GIST community as she steps away from the LRG Board of Directors. It was a special moment to see Teena receive the appreciation she so deeply deserves, including a heartfelt tribute and award presented by Gary Glasser (LRG Board President).

For so many years, Teena has brought her experience, compassion, and unwavering commitment to the GIST community, to the Board and beyond.

Her voice and perspective have made a lasting impact, and it was truly meaningful to be there at Life Fest as our community came together to thank her for everything she has given.

Teena, thank you for your years of service, your advocacy, and most importantly, for being such an important part of the LRG community. While you may be leaving the Board, your impact on this community will continue for years to come.





Rob Taylor Shares His Story with Black Health Matters

by Rebecca Pauley, Program Director



The Life Raft Group was proud to be part of "Understanding Rare Cancers: A Conversation About Sarcoma," a webinar hosted by Black Health Matters that drew more than 600 registrants eager to learn about GIST, other sarcomas, and the unique challenges these rare cancers present within the Black community.

Life Raft Group Board Member and Health Equity Council member Rob Taylor joined the panel alongside sarcoma specialist Dr. Leighton Elliot and fellow patient advocate Simone I. Smith to share both the clinical realities of sarcoma and the deeply personal experience of living with a GIST diagnosis.

A Rare Cancer Hiding in Plain Sight

Dr. Elliot opened the discussion by walking the audience through the basics of GIST: how tumors can grow silently for years, why abdominal pain, unexplained fatigue, loss of appetite, or blood in the stool are signs that warrant a doctor's visit, and why nearly one in five GISTs are discovered incidentally, often after a CT scan for an unrelated issue. He emphasized that diagnosis requires imaging followed by biopsy, and that every GIST tumor should undergo genetic (molecular) testing, both at diagnosis and again if a treatment stops working, since GIST can develop resistance over time.

Dr. Elliot then turned the discussion to health disparities: GIST is diagnosed in Black Americans at roughly double the rate seen in white Americans, yet Black patients are significantly less likely to receive the molecular testing needed to guide treatment. This gap contributes to lower survival rates overall. He was candid that the research community still doesn't fully understand why, underscoring the need for more inclusive clinical research and greater awareness within the community itself.



Rob's Story: From "Six to Nine Months" to Nine Years and Counting

Rob then shared his own journey, which began in 2016 at age 60 with a seemingly routine colonoscopy referral. What followed was a difficult path: an initial surgery that couldn't fully remove his tumor, an incorrect first line of treatment prescribed without proper mutational testing, and a devastating prognosis of six to nine months to live.

Rob described how connecting with the Life Raft Group changed the course of his care. Through LRG, he was guided toward specialized sarcoma care and ultimately connected with an oncologist who ran the correct genetic testing,

leading to the right medication for his specific mutation. Nearly nine years later, Rob is not only still here, but actively advocating for the GIST community, in particular those who are in the VA and those who do not have access to a specialist.

Rob's message to the audience was direct: get molecular testing, ask questions, and don't navigate a GIST diagnosis alone. He pointed listeners toward resources like LRG's Patient Registry, mentor program, and Health Equity Council as places to find community, information, and support.

Listening to Your Body

Simone Smith echoed the importance of self-advocacy, urging attendees to trust their instincts, keep up with routine screenings, and push back when something feels wrong, even if a doctor initially dismisses their concerns. Both she and Rob stressed that sharing their stories isn't just personal healing, it's a way to potentially save someone else's life.

Why This Conversation Matters

With over 600 registrants tuning in, the webinar reached a broad, engaged audience, many hearing about GIST for the first time. That kind of reach is exactly why the Life Raft Group values partnerships like this one with Black Health Matters: rare cancers require targeted awareness, and communities disproportionately affected by a disease deserve information tailored to their experience.

The Life Raft Group remains committed to closing gaps in GIST diagnosis and care, supporting patients like Rob at every stage of their journey, and partnering with organizations that help bring this information to audiences who need it most.

You can view this impactful webinar below.



Black Health Matters Websites:
https://ourhealthourwellness.com/
https://blackhealthmatters.com/

Social Media:
https://www.facebook.com/blackhealthmatters/?ref=bookmarks
https://www.instagram.com/blackhealthmatters/

LRG 'On the Road'

The LRG Joins with Sarcoma Advocates to Bring Patient Voices to DC

by Carol Tordella, Sr. Dr., Marketing & Communications

This summer, sarcoma advocates from across the country came together in Washington, D.C. for the Sarcoma Foundation of America's (SFA) 2026 Sarcoma Advocacy Weekend and Hill Day (July 16). The Life Raft Group was proud to be part of this collective voice for the sarcoma community.

On July 16th, sarcoma advocates – patients, caregivers, and patient advocacy organizations met with members of Congress to bring attention to the needs of people living with sarcoma. Together, we called for continued federal investment in sarcoma research, access to quality healthcare, and policies that address the challenges patients and families face. SFA's CEO Brandi Felser's reflected on the power of this type of advocacy on Facebook at the conclusion of our meetings.

Meetings on the Hill

Teams of 3-5 advocates visited the offices of dozens of representatives and senators and focused on four main legislative asks.

Our team of three – Diane W, Nate F (both survivors) and I met with Sydney Pearson (Senator John Fetterman), JP Moreland (Rep. Mike Kelly), Colton Lehman (Senator David McCormick), and Representative Glenn Thompson. We shared personal and community stories of those living with sarcoma and were able to illustrate how these legislative asks directly affect our communities.

The 'asks' were as follows:
#1 – We urged them to protect and support robust federal investments in biomedical and cancer research by funding the National Institutes of Health (NIH) at $47.3 billion, the National Cancer Institute (NCI) at $7.46 billion, and Advanced Research Projects Agency for Health (ARPA-H) at $1.5 billion in sustained funding.

#2 – We urged them support and advance:

Clinical Trial Modernization Act –
H.R.3421 House. Sponsor – Rep. Paul Ruiz (D). Status: (Introduced) Referred to the Energy and Commerce; Ways and Mean committees.
S.4440 Senate. Sponsor – Sen. Tim Scott (R): Status: Reviewed twice and referred to the Committee on Finance

Description: This bill authorizes a grant program and provides certain exemptions to support the participation of individuals in clinical trials.

Specifically, the bill authorizes a grant program to support outreach, education, and recruitment efforts for clinical trials that may benefit certain underrepresented populations or communities in need, such as rural or tribal areas.

The bill also exempts from anti-kickback laws for federal health care programs (1) remuneration that is offered to cover participants' expenses to participate in clinical trials, (2) the provision of free digital health technologies to support participation of underrepresented populations in clinical trials, and (3) payment for participants' cost-sharing obligations in relation to clinical trials.

Finally, the bill exempts up to $2,000 in remuneration that is received for participating in a clinical trial from income tax.

#3 – We urged them to support to preserve and permanently expand telehealth access with these two Acts:

Connect for Health Act of 2025-
H.R.4206 House – Sponsor – Rep. Mike Thompson (D). Status: (Introduced) Referred to the Energy and Commerce; Ways and Mean committees.
S.1261 Senate – Sponsor – Sen. Brian Schatz (D): Status: Read twice and referred to the Committee on Finance

Description: Summary is in progress. Basically, this bill is about removing specific barriers for telehealth services. It would remove several Medicare telehealth barriers, including geographic restrictions, expand eligible originating sites and practitioners, and address telehealth access through federally qualified health centers and rural health clinics. This bill would make the Telehealth Modernization Act (below) accommodations permanent. If you follow the Senate link, you can read more specific details.

Telehealth Modernization Act
H.R.5081 House – Sponsor Rep. Earl Carter (R). Status: (Introduced) Referred to the Energy and Commerce; Ways and Mean committees.
S.2709 Senate -Sponsor Sen. Tim Scott (R): Status: Read twice and referred to the Committee on Finance

This is primarily an extension bill keeping many of the existing COVID-era Medicare telehealth flexibilities in place through September 30, 2027.

#4 – We urged for support to pass this bipartisan federal legislation introduced to improve lifelong support, care coordination, and resources for the millions of cancer survivors in the United States. Many cancer survivors need resources to help monitor for secondary cancers and late and long-term effects caused by their cancer treatment. This legislation will help improve their quality of life and health outcomes after treatment.

Laine Jones Comprehensive Cancer Survivorship Act –
H.R.8839 House – Sponsor – Reps. Debbie Wasserman Schultz (D). Status: (Introduced) Referred to the Energy and Commerce; Ways and Mean committees and Education and Workforce.
S.5052 Senate – Sponsor – Sen. Amy Klobucher (D). Status: Read twice and referred to the Committee on Finance

Description: To address the health of cancer survivors and unmet needs that survivors face through the entire continuum of care from diagnosis through active treatment and post treatment, in order to improve survivorship, treatment, transition to recovery and beyond, quality of life and palliative care, and long-term health outcomes, including by developing a minimum standard of care for cancer survivorship, irrespective of the type of cancer, a survivor's background, or forthcoming survivorship needs, and for other purposes.

What can you do?
Contact your representatives and senators and ask them to sign on to support these acts. Each team we met with encouraged us to tell constituents to call in, rather than just email or write.

Educational Workshops
The next day (July 17), the sarcoma advocates gathered for an educational day with presentations which included:

– Dr. Alice Chen, Senior Scientific Officer and Head of the Developmental Therapeutics Clinic at the NCI, discussed how they decide which cancers to study and which drugs to study.

– Dr. Geraldine O'Sullivan Coyne, Director of Clinical Research at START, talked about the differences between trial investigator-initiated clinical trials and pharmaceutical initiated trials.

– An expert panel discussed Opportunities for Engagement – Dr. Jennifer Stundon, FDA, Dr. Kristen Wessel, FDA, Dr. Elena Schwartz, NCI, and Sagar Ghosh, CDMRP (Congressionally Directed Medical Research Programs)

– Dr. Samuel Blackman, physican scientist, pediatric neuro-oncologist, and cancer drug developer, and Entrepreneur-in-Residence at Google Ventures, presented on how companies evaluate and advance rare cancer therapies. [Of note: Dr. Blackman highlighted an important shift in how new medicines are being developed. While large pharmaceutical companies once drove much of early drug discovery, today many novel molecular entities and promising new therapies originate in smaller biotechnology companies. When companies decide which treatments to pursue, key factors include strong proof of concept and whether the potential return is greater than the cost of development. The treatment-addressable market, or the number of patients who could realistically receive a therapy, is an important part of that calculation. For rare diseases, this can make attracting investment more challenging, even when the science is promising.]

– Dr. Jeff Toretsky, Georgetown University, discussed challenges to Drug Development in Sarcoma.

– An expert panel shared briefly and then answered questions on how patients advocates can drive change – Terri Stewart, EMD Serrano, Abe Friedman, US House Committee on Rules, Nancy Gardiner & Jonathan Gardner, Sarcoma Patient Advocates.

For rare cancers like GIST and liposarcoma, progress takes more than good science. It takes research funding, investment in new treatments, policies that support patients, and advocates who make sure rare cancers are not left behind. These two days in Washington were a reminder of how important it is to keep showing up, sharing our stories, and speaking up for what our communities need. When we come together, our voices are stronger and can help move research and better treatments forward.

Featured Events

Join us us at a GIST Day of Learning (GDOL) this fall!

GDOL Minnesota - Sept. 26



REGISTER

GDOL San Diego - Oct. 24



REGISTER



Poker for a Purpose - Sep 24

Bring your poker face and join us for Texas Hold'em Poker Fundraiser in Oakland, NJ!

Enjoy a night of cards and friendly competition while helping support the GIST community.

REGISTER

Recordings:

Life Fest 2026 Playlist TODAY!

GIST Awareness Day featured webinar:

La importancia de los cuidados paliativos en el tratamiento oncológico

(The importance of palliative care in cancer treatment)

SUBSCRIBE TO OUR YOUTUBE CHANNEL TODAY!



End the Summer in GIST Style!

Grab your GIST Do It t-shirt today and keep the GIST community close wherever summer takes you.

GET YOURS NOW!

The Life Raft Group
973-837-9092
liferaft@liferaftgroup.org
www.liferaftgroup.org

Follow us on social media: