

The Life Raft Group Newsletter



#ThrivingTogether



OCTOBER 2024

Embracing the Journey with Mentorship & Community - Billy Bough

Facing a cancer diagnosis can often feel like navigating a stormy sea alone. For Billy Bough, diagnosed in 2020, the journey was fraught with both profound challenges and unexpected support. His story illuminates how the right mentorship and a strong community can transform the daunting path of cancer into one of hope and connection.

Billy's early days, post-diagnosis, were marred by a deep sense of loneliness, despite his involvement in a cancer support group. His breakthrough came when he connected with Jon T, an LRG mentor whose life experiences and passions resonated deeply with Bough.

"Jon and I really clicked together. It was a good conversation, and the things that were happening to me had already happened to him," Bough reflected.



Jon's guidance was not just about sympathy but about actionable advice, especially in navigating the harsh side effects of GIST treatment like cramping.

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A Message From Our Executive Director



Summer was a busy and exciting time for us, highlighted by our 11th Life Fest conference. It was wonderful to see our GIST community come together, build new friendships, learn more about GIST, and engage with leading experts.

This Fall, we were thrilled that Jerry Call, LRG Data Analyst, attended the inaugural **GISTT Summit**. This event was led by SARC with leadership from former LRG Research Team members Dr. Sebastian Bauer, a medical oncologist and researcher from West German Cancer Center, and Dr. Jonathan Fletcher, a researcher from Harvard Medical School and

Brigham and Women's Hospital. The Summit united both senior and early-career GIST investigators to discuss the latest in GIST biology, clinical and translational strategies, while fostering collaboration between scientists, oncologists, industry leaders, and advocacy groups.

The Life Raft Group was a proud lead sponsor of this important conference, and we are fully committed to future research collaborations that will arise from these efforts.

In order for our small but mighty team to continue providing essential support for GIST patients and advancing research globally, we rely on your help.

Here are a few ways you can give back:

1. Join the Patient Registry & Donate Tumor Tissue

Your participation in the registry or contribution of tumor tissue to research is invaluable. Your data helps drive scientific progress and brings us closer to better treatments.

2. Make a Donation

Your generosity fuels our programs and services. Consider becoming a GEM (Give Every Month donor) with a donation of \$10/month or more. Even small contributions make a significant impact on our work.

3. Volunteer Your Talents

We need writers, designers, strategic thinkers, event planners, and more. Even simply making phone calls can provide tremendous support.

4. Leverage Your Connections

If you know someone—a friend, family member, colleague, or neighbor—who has ties to a foundation or corporation that could offer grants or charitable support, please help us make that connection.

As a small nonprofit, we rely on the strength of our community to continue this vital work. Your involvement helps us stay connected and ensures we can support patients in need.

Thank you for joining with us. Together, we can redefine what it means to live with GIST and use our experiences to uplift and empower others.

Sara Rothschild

Executive Director

This relationship exemplifies the profound impact that a mentor's understanding can have on someone's journey. Inspired by the support he received; Bough felt compelled to extend the same kindness to others.

"I thought it was kind of my responsibility to share so that someone else might benefit from my experiences," Billy shared.

This sense of duty to offer support and break the stigma around mental health challenges like depression speaks to Bough's commitment to fostering a nurturing community. His transition from mentee to mentor underscores the reciprocal nature of support and the value of personal experience in guiding others through similar trials.



The Boughs

Bough also shared with the LRG the critical role of a specialized support group had in his GIST journey.

"Joining a support group that has a similar cancer to what you have really makes a difference," he advised.

The personalized support and understanding offered by these groups contrasted sharply with the more generalized or negative experiences he encountered elsewhere. This tailored approach not only provides practical advice but also creates a space where individuals feel truly seen and heard.

For those stepping into the world of cancer diagnosis, Bough's guidance is both practical and hopeful.

"Stay positive and find a group where you can relate to others who have the same cancer. It really does make a lot of difference," he emphasized.

By aligning with a community that understands the specific nuances of one's condition, individuals can gain both emotional support and practical insights, paving the way for a more informed and hopeful journey.

Billy's story is a powerful testament to the influence of mentorship and community in the cancer experience. His journey from feeling isolated to finding a supportive network and ultimately becoming a mentor himself showcases the profound impact of shared understanding and empathy. As we navigate the complex terrain of cancer, Bough's experience reminds us that meaningful connections and shared experiences can turn a daunting path into one of collective strength and support.



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We are making a major impact in the lives of patients and rare disease treatment guidelines, clinical trials & research.

Help us get the funding we need to keep this work moving forward!



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New SDH Tissue Testing Collaboration with the NIH & UCSD

By Denisse Evans, Sr. Dir. Data Mgmt & Research & Becky Owens, Registry Consultant



UC San Diego Health



The rarity of SDH-deficient GIST cell lines has been a major obstacle in researching this disease. Access to SDH-deficient GIST tissue is vital for advancing research to understand and treat this cancer, as tumor tissue samples can be used for developing disease models like tumor cell lines.

We are thrilled to announce the official launch of our centralized SDH-Deficient GIST Biobank which is being spearheaded by Dr. Jason Sicklick at UC San Diego and funded by the NIH/NCI. This biobank will be led by Dr. Andrew Blakely at the NIH, including all respective members of NIH, such as Dr. John Glod. The LRG will play a vital role in coordinating the identification of participants and collecting patient data for this groundbreaking project.

This is the first multi-institutional, centralized biobank established for SDH-deficient GIST in the US. We will collect high-quality, well-preserved tumor samples obtained during surgery. The samples preserved in our biobank will be made available to researchers conducting active studies.

We are now inviting patients and surgeons to contribute fresh tumor samples from SDH-deficient GIST patients. If you are involved in an upcoming SDH-deficient GIST surgery, we encourage you to consider participating in this program by facilitating tissue donation.

If you would like to participate or would like to learn more about this program, please email u01biobank@liferaftgroup.org



SDH patients, doctors & staff at Life Fest, San José

GISTT Summit 2024 - Essen, Germany

By Denisse Evans, Sr. Director, Data Mgmt. & Research



The GIST Science Translation Therapy (GISTT) conference, held in Essen, Germany, from October 16-18, was a tremendous success. This landmark event marked a significant shift in GIST research, moving from a focus on drug resistance to exploring potential cures, specifically targeting the persistence of cells that survive imatinib treatment. The Life Raft Group (LRG) was honored to serve as a platinum sponsor, with the event spearheaded by renowned researchers Dr. Jonathan Fletcher and Dr. Sebastian Bauer.

LRG representatives, including data analyst Jerry Call, UK representative Jayne Bressington, and Canadian advocate Dr. David Josephy, actively participated in the conference, further strengthening global partnerships. Jerry Call presented introductory remarks that launched the conference. All three of our representative's breakout sessions which covered multiple topics like SDH, imatinib resistance and therapeutic development.

The conference brought together experts, researchers, clinicians, young investigators and advocates from around the world. Attendance (which was 'by invitation only') was more than 100 participants. Collaborative discussions were at the forefront, with all participants working toward the unified goal of expanding therapeutic options and, ultimately, finding a cure for GIST. Key discussions focused on targeting persistent cells and moving towards combination therapies rather than relying solely on imatinib. This represents a critical step in developing more effective treatments for GIST patients. In addition to plenary presentations, there was a poster session featuring approximately 25 posters, which two posters from LRG.

Innovative clinical approaches, including "challenge trials" and neoadjuvant treatments, were also spotlighted. These approaches offer promising opportunities for early evaluation of treatment efficacy, particularly by studying residual tumors post-surgery, which could provide invaluable insights into treatment effects.



The LRG is committed to playing a critical role beyond sponsorship by actively contributing to research efforts through its vast patient registry and biobanking initiatives. As part of this commitment, the LRG will assist in providing access to valuable tissue samples from GIST patients, which will be crucial for advancing studies on persistence and drug resistance. These tissues, collected through the LRG's centralized biobank, offer researchers a unique resource to deepen their understanding of the disease and explore new therapeutic avenues.

In addition, the LRG continues to spearhead advocacy efforts on critical issues, such as the ethical concerns surrounding placebo-controlled trials in rare diseases like GIST. The LRG is actively engaging in discussions with researchers and policymakers to push for more patient-centered clinical trial designs. Through these combined advocacy and research efforts, the LRG remains a driving force in shaping the future of GIST treatment and care.

In addition to research advancements, the event emphasized the influential role of organizers in shaping the future of clinical practice. Experts like Dr. William Tap (MSKCC) emerged as leaders in this area, alongside Dr. Jonathan Fletcher, Dr. Sebastian Bauer, Dr. Jason Sicklick and Dr. Jon Trent. Their collaborative work promises to drive forward meaningful advancements in GIST treatment.

The LRG remains steadfast in its mission to find a cure for GIST. By fostering collaboration among researchers and keeping patients at the center of every decision, the LRG continues to lead efforts in advancing research and improving patient outcomes.

Attendee Data Analyst Jerry Call will report more on this conference in an article on our website this week.

Results: A total of 2,630 patients diagnosed with GIST were identified, of which 1,519 patients (57.9%) had known mutation status. We evaluated 734 advanced/metastatic GISTs by predicted IM sensitivity. While in the whole cohort mPFS was 31.2 months (95% CI 27.6-36.7), the mPFS in the IM-sensitive cohort (n=559) was significantly higher at 42 months (95% CI 36.6 - 53.9) compared to 18.8 months (95% CI 10.9 - 29.5) in the IM-intermediate cohort (n=119) and 15 months (95% CI 10.0 - 22.1) in the IM-insensitive cohort (n=120). The median overall survival (mOS) in 533 advanced/metastatic KIT exon 11 patients was 12.6 years (95% CI 11.1-14.3). The rate of extra-abdominal metastasis in 364 advanced GIST patients with KIT/PDGFR mutations and abdominal primaries was 17% (n=61), with 47 (13%) reporting thoracic metastasis and 28 (8%) reporting bone/spine metastasis. Only one patient reported a brain metastasis (0.2%).

Conclusions: Our study shows that initial IM treatment may achieve a mPFS of over three years for IM-sensitive mutations, with a mOS >10 years. Additionally, 17% developed extra-abdominal metastases, mainly to the thorax and bones. This highlights the need to integrate mutation status and clinical-genomic data from large cohorts into GIST therapeutic development and clinical counseling.

What does this mean for patients?

Imatinib has been the main treatment for Gastrointestinal Stromal Tumors (GIST) for over 20 years. In early trials, patients lived without their cancer progressing for about two years on average. To better understand how well this treatment works in the real world, we looked at data from the LRG patient registry and focused on how different types of GIST responded to IM based on their genetic mutations. We reviewed information from the LRG Patient Registry, including details like where the tumor was in the body, the genetic mutations the tumors had, and the treatments patients received.

Results from this study showed: Out of 2,630 GIST patients, 1,519 reported a mutation. Out of these, 734 patients had advanced or metastatic GIST (meaning the cancer had spread), and they were grouped based on how sensitive their tumors were to IM.

- IM-sensitive group: These patients lived without their cancer progressing for an average of 42 months (about 3.5 years).
- IM-intermediate group: These patients had an average progression-free survival (PFS) of 18.8 months (about 1.5 years).
- IM-insensitive group: These patients saw their cancer progress after an average of 15 months (just over a year).

The study also found that 17% of patients with advanced GIST developed cancer that spread outside the abdomen, most commonly to the chest and bones, but very rarely to the brain.

This study shows that for GIST patients whose tumors are sensitive to IM, treatment can help keep the cancer from progressing for over three years (this is just a median number, which means there are cases with higher numbers and lower numbers). However, some patients may still experience cancer spreading to other parts of the body, particularly the chest and bones, which emphasizes the importance of knowing the tumor's mutation when deciding on treatment.

READ MORE ON OTHER RELEVANT GIST PRESENTATIONS FROM ESMO 2024:

<https://liferaftgroup.org/2024/09/esmo-2024-summary/>

Health Equity Council Inaugural Meeting

By Sara Rothschild, Executive Director

At our first-ever Health Equity Council meeting, members from across the GIST community came together to share their personal stories and discuss the unique challenges faced by patients from underserved populations. It was inspiring to hear how deeply everyone cares about improving support for these patients, and the council is excited to make a difference.



During the meeting, we brainstormed creative ways to increase outreach and awareness of The Life Raft Group's resources, from social media campaigns to holding educational sessions with healthcare providers. We also discussed the importance of working closely with hospitals and clinics to share critical information with those who need it most.

Looking ahead, the group will continue to define roles and responsibilities and build momentum around outreach initiatives, with plans for a follow-up meeting soon. If you are interested in joining this council, please contact Sara Rothschild

at srothschild@liferaftgroup.org.

We are energized by the passion of this group and look forward to seeing how the Health Equity Council will help shape our future efforts!

Medicare Open Enrollment October 15 - December 7

Excerpted from an article by the National Organization of Rare Diseases (NORD)

Two new changes every Medicare-eligible person must know:

Starting in 2025, a law called the Inflation Reduction Act (IRA) will make two significant changes to Medicare prescription drug plans, also known as Part D plans, designed to make it easier for you to afford your prescription drugs. These changes include:

- A \$2,000 cap on your out-of-pocket expenses for prescription drugs in 2025. This only applies to drugs covered on your Medicare prescription drug (Part D) plan formulary.
- An optional monthly payment plan for your prescription drugs, called the Medicare Prescription Payment Plan or M3P, with a limit on expenses each month. You must sign up to utilize this option, which may be a better fit for certain patients with high out-of-pocket prescription drug costs at the start of the year.

Every year during the annual Medicare Open Enrollment period, it is extremely important to look at the Medicare Part D prescription drug plans available to you and check which drugs a plan covers before you sign up. Not all plans are the same. Make sure the prescription medications you take now, or expect to be taking in the upcoming year, are covered by the plan you choose.

To check if a plan covers a drug you are currently taking, or expect to be taking in the upcoming year, use the Medicare Plan Finder at [medicare.gov/plan-compare](https://www.medicare.gov/plan-compare).

To learn more about these changes to Medicare, including answers to frequently asked questions, such as what to do if your medication is not covered by your Medicare plan, read NORD's guide at rarediseases.org/medicare-ira-changes.

LIPOSARCOMA SUPPORT NETWORK

We're excited to announce the **Liposarcoma Support Network (LSN)**, a new program from The Life Raft Group, expanding support to another sarcoma community. Like GIST, liposarcoma is a rare soft tissue sarcoma with complex challenges.

LSN will provide vital resources, education, one-on-one mentoring, and a patient registry to drive research.

"No one should face a liposarcoma diagnosis alone," says Christina Wang, Volunteer Director of LSN. *"We aim to provide the knowledge, support, and community patients and caregivers need."*

Explore LSN at www.liposarcomasupport.org or email for more info: support@liposarcomasupport.org.

State Leaders Are Now 'Regional Leaders'!

By Brian Morello, Director of Development

After taking some time to evaluate our State Leader Program, we're officially changing the name of these essential representatives to Regional Leaders. Many of our leaders are taking the lead with multiple states which has led to the name change.

Our Regional Leaders are an invaluable resource for patients and caregivers by running support groups as well as helping them identify important local resources.



"I am grateful and proud to be part of the Regional Leader Program at The Life Raft Group. It gives me the opportunity to speak with patients, both recently diagnosed and long term, from different areas of the Northeast. I am able to hear their stories and journey and give them support. I am able to share my personal experience with GIST in order to help others."

- John Abrams



"We make time to get to know each other aside from our GIST. I like to find out people's hobbies and interests. I usually end the meeting by having everyone tell the group something positive in their lives."

- Pat Bonda-Swenson

If you're interested in becoming a Regional Leader, please contact me at bmorello@liferaftgroup.org



Fall
2024

Know Your Mutation:
Why is Biomarker Testing
Important in GIST?

Michelle Harris
Medical Affairs,
Tempus AI

Dr. Calvin Chao
Medical Affairs,
Tempus

November 6, 2024
1 PM ET

NOVEMBER 6, 1PM ET

VIRTUAL
GIST DAY OF
LEARNING
NORTH CAROLINA
NOVEMBER 6, 2024

NOVEMBER 6, 3PM ET

Updates
from
CTOS

Dr. Thierry Alcindor
Dana-Farber Cancer Institute

November 25, 2024
12 PM ET

NOVEMBER 25, 12PM ET

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