



Enhancing survival and quality of life for people living with GIST

DECEMBER 2023

Our Thriving Together Holiday Campaign is in full swing and we want to express our deepest gratitude for your continued support. You are a beacon of hope for those facing the challenges of gastrointestinal stromal tumor (GIST). Thank you for joining us in the pursuit of a cure and empowering patients to thrive.

We are still working hard to reach our goal for this campaign (\$50K), so please give what you can and share the mission of The Life Raft Group with your family, friends & colleagues this holiday season.

bit.ly/Holiday2023Campaign

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In Loving Memory: Elizabeth Harries, James Gallant, Owen Moore, Nandini Dabbir, Lidia Korniyenko, Malu Gawthrop, Peggy Kubert, Nitin Kumar, Gregory Hobbs, Roberta Carson, Cindy Farr, Judith Ferguson

Notes from Our Executive Director

As we bid farewell to the year, it's time to reflect on the journey we've shared in the GIST community. This year, we focused not just on survival but on thriving. We engaged with patients worldwide, discussing self-advocacy, fundraising for research, and embracing life despite the challenges of a rare disease. We witnessed the expansion of clinical trials in our disease space and contributed input regarding the patient perspective and trial locations. We also pushed for better access to GIST treatments globally.

What unites us is the strength of this community, a support system that spreads awareness and helps us achieve our goals. This year, we expanded our global mentor program, reaching more patients and caregivers with our support services. Additionally, we introduced more treatment and gene-specific support groups, providing avenues for subsets of patients to connect.

At major conferences like ASCO and CTOS, our presence was impactful, ensuring the resounding voice of the GIST community in influential spaces. Furthering our advocacy efforts, we published a pivotal article in Nature Medicine, challenging the conventional use of placebos in clinical trials. This contribution is a testament to our commitment to pushing the boundaries of advocacy for the benefit of the GIST community. Already, its impact is evident, with studies citing it as an example to reshape the design of research study comparison arms.

Our conversations extended beyond medical aspects to living life fully despite GIST challenges. Patients shared stories of resilience, finding joy in the journey. This spirit encourages others to navigate life's obstacles with courage.

As we look ahead, our commitment to thriving, supporting one another, and advancing research remains strong. For the first time, we've committed funds to support a clinical trial in GIST. We invite you to contribute to our cause, helping us continue the journey towards a future where GIST is conquered.

Together, as a community, we will collaborate to advance progress in our understanding of the disease. Here's to the year behind us and the journey that lies ahead – sailing strong, united, and determined.

– Sara Rothschild

New Clinical Trials Focus for the LRG in 2024

by **Denisse Evans**, Senior Director, Data Management & Research

I'm thrilled to announce a new initiative aimed at bringing you the latest and most relevant information about ongoing clinical trials: "Clinical Trials Wednesday".

Starting in January, every Wednesday will be dedicated learning about clinical trial process and to highlighting the groundbreaking clinical trials focused on gastrointestinal stromal tumors (GIST).

We understand the importance of staying informed about the latest advancements in research and treatment options, and we want to empower you with the knowledge to make informed decisions about your healthcare journey.

Clinical trials are the backbone of medical progress, serving as the driving force behind the development of new treatments and therapies. Understanding the details of these trials is crucial, as it empowers you to make informed decisions about your healthcare, demystifies the process, and ensures you play an active role in shaping the future of GIST treatment.

What to Expect on Clinical Trials Wednesday

- In-depth insights into ongoing clinical trials for GIST. Dive deep into specific ongoing clinical trials, understanding their goals, methodologies, and potential impact on GIST treatment.
- Updates on innovative treatments and therapies in development.
- Expert commentary from leading oncologists and researchers.
- Resources to help you navigate and understand the world of clinical trials.

Why Clinical Trials Matter

Clinical trials play a pivotal role in advancing medical science and improving patient outcomes. By participating in or staying informed about these trials, you contribute to the collective effort to find more effective treatments for GIST. Your involvement can make a real difference not just for you, but for the entire GIST community.

How You Can Get Involved

- Follow our social media channels for updates and highlights.
- Share this initiative with your fellow GISTers and caregivers.
- Stay engaged, ask questions, and be part of the conversation.
- We are committed to supporting you on your journey, and Clinical Trials Wednesday is one more way we will provide valuable information and foster a sense of community among GIST patients.

Together, we can make significant progress in the fight against GIST. Here's to knowledge, empowerment, and a brighter future!

If you have any questions, please contact The Life Raft Group at info@lifteraftgroup.org

Lessons in Thriving with GIST

Welcoming a New Global Liaison - Donncha Lynch

by **Carol Tordella**, Director, Communications

In 2012, Donncha and his wife, Oihana, relocated from Ireland to Australia due to an economic recession. Despite the promising job opportunities 'down under,' facing GIST away from family and old friends presented a significant and unexpected challenge.

Donncha initially experienced common symptoms like abdominal pains and constipation, leading to inconclusive test results. Despite a misdiagnosis of a parasite and rounds of antibiotics, he remained distracted by life's busyness until a severe attack left him unconscious. Rushed to the emergency room, suspicions of a heart attack were replaced by the discovery of a large tumor and several smaller ones in his gastrointestinal tract, marking five challenging days for Donncha.



"I was first told it was potentially another type of cancer with a very poor prognosis. So those first five days (in hospital) were something you never want to go through," said Donncha.

After concluding it was GIST and not another cancer, he began imatinib resulting in tumor reduction evident at his 12-week scan.

Donncha didn't know much about GIST or The Life Raft Group yet, but he was determined to learn all he could. He was classified as wildtype and needed to know more.

"I set out to empower myself. Through Google, I found The Life Raft Group and to be honest I probably read every article on the website. I watched a majority of the webinars. I learned about everything - molecular testing; all the terminologies. I started to make connections through the Facebook groups and through the Australian/New Zealand GISTers, and I met some Life Raft Group people through that sharing. These were some really good conversations," said Donncha.

The surgeon on his multidisciplinary medical team was not hopeful about Donncha's situation.

"I decided to seek a second opinion. The surgeon who was part of the multi-disciplinary team and who cared for me since day one had said a few times, "It's a big operation, Donny. It's going to be 9 or 10 hours and you might have physical consequences that could be very challenging for a very long time." I decided to seek a second opinion. so the search for someone else began." Donncha shared.

Donncha, after consulting with a highly experienced GIST surgeon, opted for surgery despite complications that extended the recovery. Fortunately, the outcome included clear margins, a more optimistic prognosis, and post-surgery scans indicating no evidence of disease. Test results classified him as exon 11, and due to the tumor's size and location, he's considered high-risk, requiring ongoing imatinib treatment. Overall, a significantly improved prognosis compared to those first five days.

As liaison, Donncha is eager to share what he's learned about how to live with GIST and about being a self-advocate. His goals in this role are to empower people to go out and find answers, connect with others on this journey, and to encourage others to get professional mental health services even if they don't think they need it.

"In this role that I'm doing for The Life Raft Group, I am engaging with people. I'm sharing my story. There's a bit of courage involved but that's where the most rewards come. When support was offered to me for mental health, and though I'm a very optimistic person, I went to see a psychiatrist. At first I thought it would just be ticking a box, but I met a really good psychiatrist..."

Continued on page 5

...and got a tremendous lot from the sessions. She really knew where I was coming from. She involved my family. She taught me how to talk to my nine-year old daughter, Haizea. Oihana came along for some sessions and she learned a lot about how to deal with her own suffering."

Support groups are important:

"I'm in this men's mental health management group here in Sydney and we meet for a swim and a coffee once a week. They're a great bunch of guys, all at different stages of life; some are going through relationship issues, some addiction issues, some health battles. I can't explain the rush of endorphins or whatever that is, to be able to share your story in a circle of trust."

His best advice for newly diagnosed patients is educate yourself.

"I know not everyone is tech savvy or likes to read, but join the LRG, find someone on the same journey to connect with. If I hadn't done these things, I might not have gotten the mutational testing, or a second opinion. For all I know, I might not have been here talking to you if I didn't do my research and find another surgeon, who did an amazing job that didn't have catastrophic effects on my physical activities."

A very big part of having GIST is realizing how much your perspective on life changes:

"I have down moments event though I probably come across as a very strong guy, but you will have some very sad moments, and through this I've come closer to God, have more intimate relationships with my family, I'm leaned into mindfulness and meditation and I'm very invested in being self-aware and being a better man. I've no idea how long I have and I want to be the best version of myself from now til whenever. I want to give it 100% as often as I can and be ok with it when I can't. This experience has changed the way I look at life so drastically. I would have never have thought of these things before."

Patients stories illustrate the heart of the a patient's journey living with GIST. Stories like Donncha's not only encourage and inform our community, but help others know that they are not alone. If you would like to read more member stories, please visit <https://bit.ly/LRGMemberStories>. We encourage you also to share your own story and consider volunteering with the LRG in one of the many patient & caregiver support roles, such as a liaison or support group leader, or a GIST Mentor.

To share your story, contact:

Carol Tordella: ctordella@liferaftgroup.org

To volunteer, contact:

Diana Nieves: dnieves@liferaftgroup.org

THRIVING TOGETHER *Holiday Campaign*

Help us support patients across the globe! Click button, use QR code or use the URL to donate.

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The 2023 ESMO Congress

by **Sahibjeet Parmar**, Director, Data Management & Research



The European Society of Medical Oncology Congress was held in Madrid, Spain October 20-23, 2023. This meeting is a highly influential oncology platform for clinicians, researchers, patient advocates, journalists, and healthcare industry representatives from all over the world. There were 155 countries represented through 207 sessions. Over 33,000 participants including over 580 speakers attended the Congress at the famous IFEMA Madrid. In addition, 2,545 abstracts were presented with 198 mini-orals and 2,200 posters.

The Life Raft Group's Executive Director, Sara Rothschild and I attended this year's ESMO Congress. This was the first time The Life Raft Group has attended ESMO. We are proud to share that two of our abstracts were accepted as posters.

We attended GIST and sarcoma focused sessions including a session sponsored by Deciphera Pharmaceuticals on the expert perspectives: management of advanced GIST - now and in the future; a session on genetic predisposition in patients with sarcoma; mini oral sessions that included updates on clinical trials for GIST patients; ctDNA in relation to tumor volume in GIST; and other sessions that were generalized to sarcoma management.

The Life Raft Group team was proud to be recipients of the ESMO Patient Advocate Travel Grant which helped support travel for the conference. To receive the grant, we attended all the patient advocacy focused sessions that were held during the conference. These meetings were very informative on how to support patients and caregivers as a patient advocacy organization.

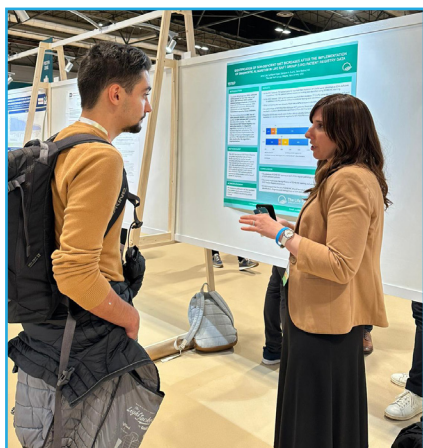
When we were not presenting our poster, attending GIST and sarcoma sessions or patient advocacy sessions, they were able to meet with industry partners to discuss ways



Sebbi and Sara meet with Dr. David Thomas, CEO of Omico: Australian Genomic Cancer Medicine Centre

to further strengthen the relationship between the LRG and industry to better support patients relating to access to treatment and care. We also met with leading researchers and clinicians from all over the world to discuss future collaborations and to push research further and discuss how we can work together to increase research.

ESMO Congress 2023 was a very fruitful meeting that allowed for the LRG to present two posters, connect with leading physicians and researchers, network with industry and raise awareness of The Life Raft Group's presence within the patient advocacy community as well as the research community as an organization that is devoted to supporting patients through research and advocacy.



Sara discusses our LRG poster with a participant at ESMO

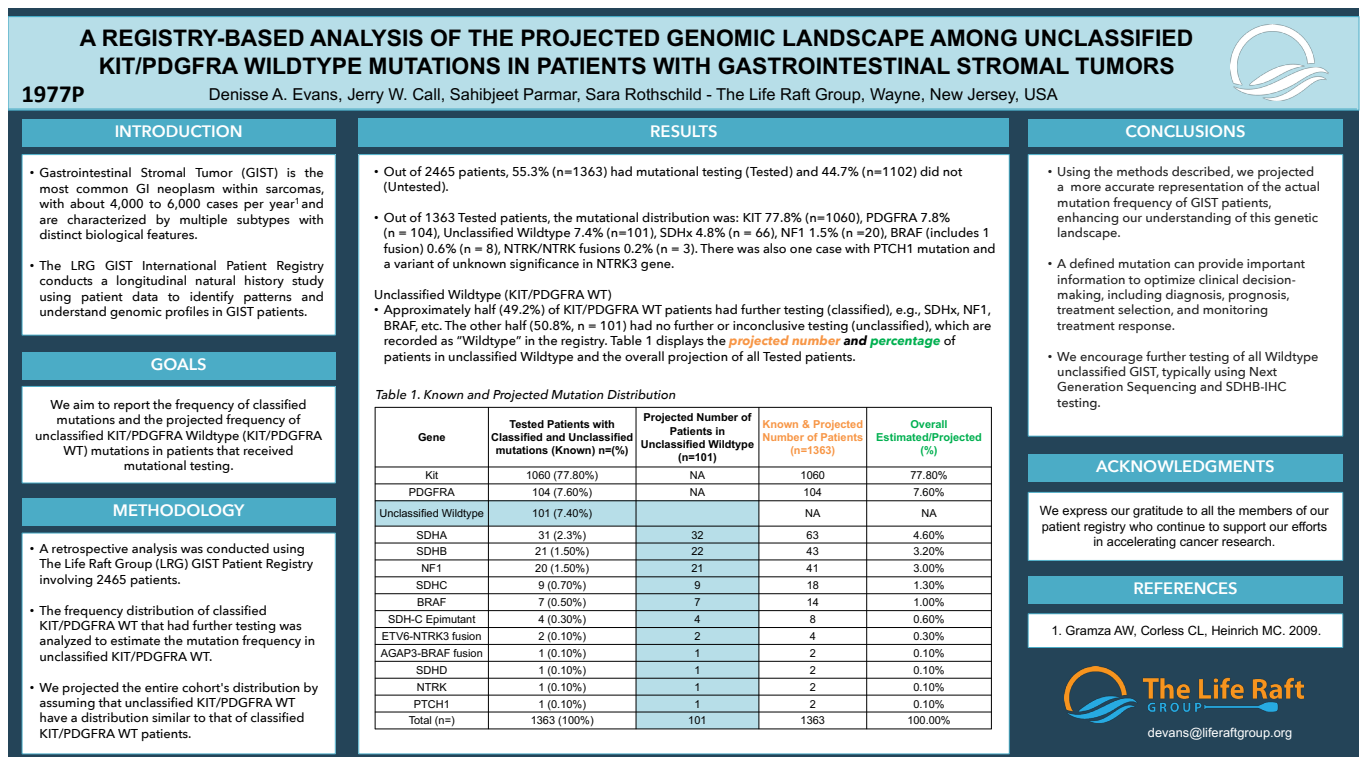
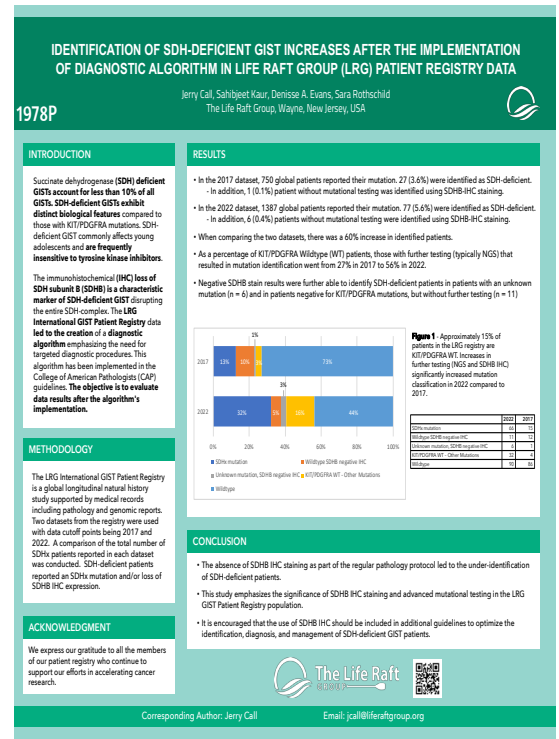
Continued on page 7

Identification of SDH-Deficient GIST Increases After the Implementation of Diagnostic Algorithm in Life Raft Group (LRG) Patient Registry Data

- This study used a diagnostic algorithm that was created due to the LRG GIST Patient Registry which emphasizes the need for targeted diagnostic procedures. The algorithm has been implemented in the College of American Pathologists (CAP). The objective of the study was to evaluate data results after the algorithm's implementation. Results included a comparison of the LRG GIST Patient Registry's 2017 dataset with 2022 dataset. The 2022 dataset had an increase of 60% of identified SDH-deficient after using the diagnostic algorithm.

A Registry-Based Analysis of the Projected Genomic Landscape Among Unclassified KIT/PDGFR Wildtype Mutations in Patients with Gastrointestinal Stromal Tumors

- This study aimed to understand unclassified and unclassified KIT/PDGFR Wildtype (WT) mutations. The frequency was completed by using retrospective data from LRG GIST Patient Registry and calculating the frequency distribution of classified KIT/PDGFR WT who had further mutational testing than just KIT/PDGFR mutational testing and using that distribution to estimate the mutation frequency in the unclassified KIT/PDGFR WT. The estimation allowed to project the entire cohort distribution by assumption that unclassified KIT/PDGFR WT would have a distribution similar to that of classified KIT/PDGFR WT patients. The estimation allowed for a more accurate representation of the actual mutation frequency of GIST patients, enhancing the understanding of GIST genetic landscape within the LRG GIST Patient Registry.



The Life Raft Group's Impactful Participation at the CTOS Conference

by **Denisse Evans**, Senior Director, Data Management & Research

On November 1st to the 4th, Executive Director Sara Rothschild, Senior Director of Data Management, Data Analyst Jerry Call, and I attended the Connective Tissue Oncology Society (CTOS) conference in Dublin, Ireland. The conference provided a platform to highlight the crucial role of collective efforts in advancing research, patient care, and advocacy in the field. One ultra-rare Sarcoma session emphasized the urgency and significance of collaborative work in the sarcoma landscape. The Life Raft Group continues to work towards closing the gap and strengthening collaborations among multiple institutions for unification and advancement in Sarcoma research.

A notable mention during the conference was The Life Raft Group's recent publication in *Nature Medicine*, focusing on the intriguing topic of placebos. This paper added a valuable dimension to the discussions, providing insights into a nuanced aspect of sarcoma research. The conference offered a conducive environment for networking with new colleagues and reconnecting with familiar faces. Interaction with the broader scientific community was enriching, allowing for the exchange of ideas and experiences.



Sara, Denisse & Jerry enjoyed hearing GIST research updates from leading expert Dr. Sebastian Bauer from the West German Cancer Center



Medical Advisory Board Meeting (not all members present) Dr. Jason Sicklick, Dr. Neeta Somaiah, Dr. César Serrano, Dr. Michael Heinrich, Denisse, Jerry & Sara.

As part of the conference agenda, The Life Raft Group actively participated in the CTOS Sunrise Mentorship meetings. These sessions offered valuable insights into different topics, ranging from how to get involved in CTOS to global networking opportunities. The engagement with other members further strengthened the commitment to collaboration and knowledge-sharing.

The conference featured diverse sessions, including "Improving Sarcoma Care Globally," "Immunology and Immunotherapy," "Novel Diagnostic and Bioinformatics," "Adolescent and Young Adult Sarcomas," "Clinical Trials in Progress," "Preclinical Models and Translational Research," and a comprehensive session dedicated to GIST. These sessions provided a comprehensive overview of the current advancements and challenges in sarcoma research and care.

A significant highlight was the strategic planning session with the medical advisory board, where upcoming projects and publications were discussed. Brainstorming sessions paved the way for innovative ideas and plans for 2024. During the conference, the team had the privilege of meeting with multiple patient advocacy group leaders. Engaging with other advocacy groups proved to be a mutually beneficial experience, fostering support and shared learning among diverse communities dedicated to tackling rare diseases.

A pivotal moment occurred during a meeting with Dr. Joanna Pryzbyl, McGill University Health, and Dr. Xiaolan Feng, University of Calgary, and Dr. David Josephy, GIST Sarcoma LRG Canada, to kick off an exciting biomarker testing project. The aim is to study key biomarkers to enhance prognostic tools, aiming to detect recurrent disease early for timely consideration of more aggressive treatments. The Life Raft Group's commitment to advancing research was evident, as this project, jointly funded by the LRG as well as GIST Sarcoma LRG Canada, promises to contribute significantly to the understanding of sarcomas.



Denisse & Sara meet with Drs. George Demetri and Michael Heinrich as well as Jessica Christo of IDRx during the CTOS poster session

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CTOS article continued from page 8

In addition to engaging with patients, caregivers, and advocacy groups, The Life Raft Group actively participated in meetings with key pharmaceutical representatives during the conference. These discussions proved invaluable, providing a unique opportunity to glean essential insights into ongoing clinical trials and the latest advancements in sarcoma treatment. The organization prioritized these interactions to stay abreast of cutting-edge developments in the pharmaceutical landscape. Learning key information about clinical trials, potential therapies, and emerging treatment modalities further empowered The Life Raft Group to be a well-informed advocate for the sarcoma community. These fruitful exchanges with pharmaceutical representatives underscored the importance of collaboration between patient advocacy groups and industry partners in advancing research and improving outcomes for individuals affected by sarcomas.

The Life Raft Group had the honor of presenting in the GIST session, where Jerry Call highlighted the organization's impactful contributions. The title of this presentation was "Recurrence-Free Survival in Gastrointestinal Stromal Tumors Is Correlated with Mutation Type: Results from the Life Raft Group Patient Registry." During his presentation, he emphasized the multiple variables that play a role in the recurrence among patients. He also announced that the organization will be embarking on a multi-institutional project with members from the US, Spain, Poland, Norway, Germany, Netherlands, Canada, and Australia, to understand and optimize risk classification in GIST. The team is very eager and excited about this upcoming collaboration.



Jerry Call presenting on stage about LRG research at the CTOS conference.

Additionally, the team was also involved in Dr. Ashwyn Sharma's oral presentation from UCSD Moores Cancer Center, showcasing the collaborative spirit within the scientific community. "Application of Single Nuclei RNA-sequencing of Human Gastrointestinal Stromal Tumors to Define Tumor Cell States for Inferring Intra- and Inter-tumoral Heterogeneity from Bulk Transcriptomes" discussed the intra- and inter-tumor cell heterogeneity of human GIST.

Closing the conference on a high note, The Life Raft Group presented two posters, titled "Longitudinal Follow Up of Gastrointestinal Stromal Tumors: Data from The LRG International Patient Registry" and "SDH Natural History Study." These posters showcased the organization's dedication to advancing knowledge and understanding in the field of sarcoma, as well as an important outcome from the data collected within our GIST patient registry. The organization would like to thank its patients and caregivers for their infinite support and participation in the patient registry.

Additionally, amidst the packed conference schedule, The Life Raft Group had the distinct pleasure of meeting with a caregiver of one of our youngest SD-deficient GIST (Succinate Dehydrogenase) patients residing in Ireland. Despite the demands of the conference, the organization made a dedicated effort to carve out time for this special interaction.



Upon reflection, The Life Raft Group expressed immense satisfaction with the successful outcomes of this conference. The wealth of knowledge gained, collaborative initiatives established, and the enthusiastic participation in various sessions reaffirmed the commitment to supporting sarcoma research. Looking forward, The Life Raft Group remains dedicated to contributing to the global efforts aimed at improving outcomes for individuals affected by sarcomas and reinforced the organization's commitment to providing support and understanding to patients and their caregivers around the globe. The personal connection made during this encounter further fueled The Life Raft Group's passion for advocacy, research, and collaboration in the fight against sarcomas. It was EPIC!

Life Fest 2024

SAN JOSÉ
California

Get ready to bask in the sunshine and soak up the vibrant energy of San José, California, as we gear up for this year's sizzling edition of **Life Fest July 19th - 21st**. Nestled in the heart of Silicon Valley, this biennial extravaganza is not just an 'event'—it's a fusion of global GISTers, caregivers, clinicians, researchers, and healthcare professionals converging in the dynamic city of San Jose.

Picture this: a hundred or so GIST warriors and their support crew uniting for an extraordinary weekend of education and celebration of

life. Life Fest isn't your average get-together; it's a full-on party of resilience and the unbreakable spirit of our global GIST community. Every participant becomes a thread in the rich tapestry of our shared journey.

And let's not forget the backdrop—the lively streets and cityscape of San José add an extra layer of magic to our festivities. In between palm trees and city lights, attendees get the chance to connect with fellow patients and caregivers, forming bonds that go beyond medical charts and institutions. Because tackling GIST isn't just a challenge; it's a journey shared with others who understand.

Our lineup of experts and healthcare professionals bring a touch of Silicon Valley innovation to the mix. With presentations and panels covering everything from GIST 101 to a focus on SDH, you're in for the latest scoop on GIST treatment and research.

So, grab your shades, mark those calendars, and come join us in San José. Life Fest 2024 is more than an event; it's a celebration of life, a gathering of kindred spirits, and a testament to the unstoppable strength of those facing the GIST journey together. *See you in San José, where the sun is shining, and the spirit is high!*

The LRG has secured two blocks of hotel rooms for guests stays at two price points. Both are special group rates which are available to participants until June 18, 2024.

Conference site hotel: Signia Hilton San Jose, 170 S Market Street, San José, CA 95113.

Hotel # 2 - Rooms are available at the Hilton San José at a different price point. This hotel is within walking distance from our Life Fest conference site at the Signia. Hilton San Jose, 300 Almaden Boulevard, San José, CA 95110.

See event page for airline discounts too!

Questions? Please reach out to Diana Nieves at dnieves@lifteraftgroup.org

REGISTER

bit.ly/EventbriteLifeFest2024



Night to Fight Cancer

by **Brianna Enciso**, Associate Development Manager

The 20th Annual Night to Fight Cancer (NTFC) benefiting The Life Raft Group's research programs hosted by Jerry Cudzil took place on October 19th, 2023, at the Midtown Loft & Terrace in New York City. This was Jerry Cudzil's final year hosting Night to Fight Cancer and he will be sorely missed.

The Life Raft Group is so grateful for Jerry's dedication and commitment to this event the past 20 years. With close to 200 participants, \$116,000 was raised!

"Thank you from the bottom of my heart, thank you for the charities and for everyone who supported us this year; it means a lot, thank you!" said Jerry, about this year's event.

Our attendees enjoyed food by Scoози Events such as Nashville Hot Chicken Served with House Slaw Pickles, New England Lobster Roll with Warm Buttered Bun and Old Bay Chips, Texas BBQ Smoked Pulled Beef Slider with Potato Salad, and the New Mexico Chicken Tinga Tacos. The specialty cocktail of the evening was the "Blackberry Margarita" with the guests finishing their night with assorted cookies, and cocktail gummy bears.



The exciting poker action took place on the main floor as guests also partook in casino games on the Terrace floor with the light of the Empire State shining in.

The big winners of the night were players Frank Garofalo in 1st place, Alex Sugarman in 2nd place, and Paul Trotta taking 3rd place.

A special thank you goes out to our corporate sponsors who included Spade Sponsor (\$20K) **Jefferies**; Diamond Sponsors (\$15K): **Bank of America** and **RBC Capital Markets**; Club Sponsors (\$10K) **Tradeweb** and **Trumid**; and Heart Sponsors (\$5K) **Cantor Fitzgerald** and **Morgan Stanley**.

We also want to thank all those individuals who helped make this event possible! Thank you to our NTFC Ambassadors **Benji Chung, Brian Behrens, Lyon Carter III, Todd Scolnick, Jayne Huang, Lauren Kling, Sophie Gitlin, and Justin Oplinger** for their continued support year after year. In addition, we would like to thank our volunteers Jared Shuster and Alaina Albanese, and our award donors: *Sojo Spa, Target, New York Giants, New York Red Bulls, and Gary's Wine.*



Left to right: Board President Gary Glasser, Paul Trotta, Frank Garofalo, Alex Sugarman, and host & Past Board President Jerry Cudzil.

Cooking to Fight Cancer - Personal Fundraiser Success!

by **Diana Nieves**, Chief Development & Involvement Officer



The Cooking to Fight Cancer event was a delicious success! In addition to the amazing in-person event, many answered LRG Board Member John Abrams' call to support the Life Raft Group beyond what was imagined. The event was sold out and took place at the splendid Uncorked Kitchen in Centennial, Colorado, on October 28th from 6-9PM, following the GIST Day of Learning at UC Health in Aurora, Colorado.

The evening at *Uncorked Kitchen* was a delightful culinary journey, guided by the skilled chefs who helped the participants craft exquisite dishes, shared heartwarming stories, and enjoyed the camaraderie of like-minded individuals. The participants cooked the Lighter Side menu which included a grilled jumbo shrimp with smokey tomato glaze as an appetizer followed by a mixed green salad with endive, watercress with pomegranate, shaved pecorino and a lemon shallot vinaigrette. The main entree included a linguini, roasted herb and lemon chicken, butternut squash, brown butter and sage cooked to perfection. Finally for dessert, a blueberry hard cider skillet pie with ginger whipped cream was made and enjoyed by all. Together, they created lasting memories and, more importantly, made a significant impact on the lives of GIST patients and their caregivers.

This event along with John's peer to peer fundraising efforts raised \$40K towards fueling GIST research. We are grateful and humbled to John, and his family and friends who support LRG's mission.



GDOL Colorado

by **Laura Occhiuzzi**, Deputy Executive Director

It wouldn't be Denver in October without a snowstorm. Despite the weather, 42 registrants attended the first GIST Day of Learning held at University of Colorado Anschutz Medical Campus on October 28th. It was an interesting program consisting of the following topics: 'GIST Pathology' presented by Lindsey Westbrook, MD; 'Surgical Management of GIST' presented by Martin McCarter, MD; Medical Management of GIST" presented by Alessandra Maleddu, MD, 'Treatment of GIST Beyond Imatinib' presented by Anthony Elias, MD; and "Clinical Trials & Future Directions" presented by Breelyn Ann Wilky, MD. John Abrams, DDS, The Life Raft Group's Colorado State Leader, provided a touching patient testimony to the group. John was a wonderful host during our weekend in Denver. Laura Occhiuzzi, Diana Nieves, and Carolyn Dewalt from The Life Raft Group attended the weekend event. GIST Days of Learning are a wonderful opportunity to learn from our dedicated specialists and to meet members of the GIST community.



If you are interested in an event in your state, please reach out to Diana at dnieves@liferaftgroup.org.

Water of Life

by **Brianna Enciso**, Associate Development Manager

Dr. Matthew Lurin's Eighth Annual Water of Life Whisky Fundraiser was held on November 8th at Keens Steakhouse in New York City. There were 50 people in attendance which included brand ambassadors and participants.

With the set up of a whisky-speed dating tasting, throughout the evening guests were able to sample a variety of different brands of whisky and enjoy Keen's Legendary Mutton Top or Prime Filet Mignon with a side of green beans and mashed potatoes. Guests had the experience of talking with the brand ambassadors and learned how their brands' whiskys were made, the history of the brand itself while enjoying the tasting. It was a great night for everyone to meet whisky aficionados and new whisky lovers while helping to raise funds for GIST research.

The Water of Life event is held in memory of Matt Lurin's stepfather, Joe Temperley, who was a GIST patient. Mr. Temperley introduced Matt to the world of whisky.

"We hope to continue this tradition of introducing others to whisky's finer aspects with this event while raising funds for GIST research and education for many years to come," stated Lurin.

Towards the end of the night, we ended off the night with raffles and cigars. Overall, the participants had an amazing night and great experience with whisky tasting while helping to raise funds for GIST research.

Webinar Recordings

Go to our YouTube channel to view the latest GIST education recordings!



Subscribe to our Channel today!

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Thank you to our 2023 Webinar Sponsors



GIST Updates from CTOS

November 27th, 2023 • 5:00pm ET



Dr. Herbert Loong
The Chinese University
of Hong Kong



Matching Biomarkers to Disease Biology & Therapy

December 7th, 2023 • 1:00pm ET



Dr. Jason Sicklick
Moore's Cancer Center
UC San Diego Health



*Thank you to our 2023
GIST Day of Learning (GDOL) Sponsors*



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**FRIDAY
NOV 17**
3-5:30 PM ET

2023
**VIRTUAL
GIST DAY OF LEARNING
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Calendar 2024

Virtual Support Groups

VIRTUAL GISTer SUPPORT GROUP

1st & 3rd Tuesday
of Each Month
6:00 PM - 7:30 PM ET



**Virtual GISTers Support Group
Meets 1st & 3rd Tuesdays**

Virtual Caregiver Support Group

1st Wednesdays
of the Month
1pm-2pm ET



**Virtual Caregiver Support Group
Meets 1st Wednesdays**

Please contact Diana Nieves at dnieves@liferaftgroup.org to join.



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GISTCHAT

**A private email community
for GISTers**

<https://forum.gistchat.org/>

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

Thank you to our G.E.M. members!

GIVE EVERY MONTH



Opal Level

Ron Cotoni
Linda Gosser
Cheryl
VanDeKerkhove
Elizabeth Skree
Charlie Grana-Benn
Claire Monaghan



Ruby Level

Heather Anderson
Rene Carrillo
Evelyn De Mello
John Driscoll
Catherine Dunn
Michelle DeValera-Gibson
Sharon Genovese
Janet Hines
Derek Kaufman
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Jennifer & Owen Moore
Rick Paczewski
Alberta Tate
Rob Taylor
Bill Borwegen



Sapphire Level

Beverly Chalmers
Christa Pereira
Gilbert Tisdale
Robert Sholiton
Danielle Williams



Emerald Level

David & Jodi Alexander
Peter Jacobson
S. Foudeh



Diamond Level

Liana Baldor
BST Consultants
Lucina Stricker
Jon P. & Lori Treder
Wes and Jacob Treder

Why Become a GEM?

<https://liferaftgroup.org/donate-2/>

A. It's convenient for you.

Your donation of \$10 a month or more can be automatically paid each month. No fuss or remembering to send in a payment.

B. It's a consistent source of funding.

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

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We are always looking for more volunteers to help with events, website & communications, science, support groups & fundraising.

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