



THRIVING TOGETHER

Annual Report 2023



THRIVING TOGETHER

In 2023, we focused on the theme of “Thriving Together”. Thriving Together represents growth, progress, transformation, change, and innovation. We will explore new ways in which we can reach out and help each other and other rare disease communities to not just survive, but thrive. We increased data collaborations with investigators, enhancing our GIST patient registry and tissue bank, and creative awareness & outreach strategies. We are committed to focusing on personalized contact with our patients through support groups, mentorship, and education.



A MESSAGE FROM OUR EXECUTIVE DIRECTOR



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

Executive Director



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DEVELOPMENT

The Development & Involvement (D&I) team functions as the foundation for building programs for patients and caregivers through facilitating global support groups, a global mentoring program, and educational days of learning throughout the US. D&I team also trains mentors, facilitates fundraising initiatives that include events, GIST Do IT Walks, and peer to peer fundraising campaigns.

In 2023, The Life Raft Group successfully executed various initiatives through close collaboration with dedicated volunteers, and rare disease advocates. Notably, the organization hosted impactful in-person events, demonstrating its commitment to community engagement. The Annual Water of Life took place at Keens Steakhouse in NYC, hosted by Dr. Matt Lurin. The 20th Annual Night to Fight Cancer unfolded at Midtown Loft in NYC, guided by the leadership of Board Member Jerry Cudzil. Adding a flavorful touch to fundraising efforts, the first Cooking to Fight Cancer occurred at Uncorked Kitchen & Wine Bar in Denver, CO, with Board Member and GIST Mentor John Abrams at the helm. The collaboration extended beyond these events, as passionate community members, including GIST Mentor David Wolfe and advocate David Perry, organized impactful fundraisers such as Know the GIST/Fight the GIST and an annual event at Vinyl Destination in Lowell, MA, contributing to the vital programs of The Life Raft Group.

The steadfast support from our dedicated Give Every Month (GEMs) members, numbering 35 strong, has been instrumental in sustaining our ongoing initiatives. Additionally, the organization has partnered with several enthusiastic members who generously organize birthday fundraisers throughout the year, further contributing to the collective effort of fundraising for the LRG.



Regular support group meetings, both in the U.S. and globally, create valuable spaces for members to connect, share experiences, and find solace in the understanding of a community that truly cares. The GIST Mentor Program stands as a dedicated initiative committed to providing essential support for individuals grappling with GIST and their families as they navigate the intricate landscape of diagnosis and treatment. Serving as a guiding light, this program empowers patients and caregivers with the necessary tools for self-advocacy while extending a compassionate hand of emotional support throughout their GIST journey. Comprising survivors and caregivers, our

LRG GIST Mentors play a pivotal role in offering understanding and empathy, ensuring that patients and their support networks feel a sense of unity on their GIST journey. Since its launch in 2019, the GIST Mentor Program has witnessed remarkable growth. In 2023, we proudly featured 27 mentors and provided invaluable support to 374 mentees in the United States. Facilitated with skill by Santy DiSabatino, a devoted patient advocate and LRG Board Member, alongside our international program director, Piga Fernández, who serves as our Global Coordinator.

In 2023, we hosted five GIST Days of Learnings (GDOLs), showcasing the organization's commitment to education and collaboration. Two in-person GDOLs were conducted in Denver, CO, in partnership with the University of Colorado Anschutz Health, and in San Francisco, CA, in collaboration with Stanford University. Additionally, virtual GDOLs were organized in collaboration with Tennessee's Vanderbilt University, Michigan's Rogel Cancer Center, and a smaller day of learning involving our Mentors and Dr. Gina D'Amato of Miami's Sylvester Comprehensive Cancer Center.



These events, whether in person or virtual, brought together a total of over 300 members within our community. The diverse collaborations and educational forums underscore The Life Raft Group's dedication to providing valuable insights, fostering connections, and advancing knowledge within the GIST community.

& INVOLVEMENT

INFORMATION, EDUCATION & ADVOCACY

In 2023, the LRG continued to prioritize effective educational programs for patients and caregivers to empower them to advocate for themselves and take a larger role in their care. When patients are armed with the latest information from global experts in GIST/sarcoma research, they are more likely to ask questions, research different options, and navigate themselves towards the best possible treatment path.

We experienced an uptick in patients from other countries wanting our information in their language. In response, the LRG partners with GIST Advocates to provide Spanish, French, and German translations to educational materials, with our ultimate goal of being a multi-lingual resource for patients all over the world. Patients drive our work forward. Every webinar, educational outreach, and campaign is based on conversations we have daily with patients about what is most important to them. We are proud to provide information that patients need in a format that is accessible to them, as we know how important this information is for patients to survive and thrive with GIST.

The Life Raft Group partnered with experts in the field and GIST Patient Advocates to host twelve webinars in 2023. All webinars are available for patients to refer to on our website and YouTube channel. Topics and speakers of 2023 webinars were:

La Senda Verde Tour

Speakers: Caregiver Vicky Ossio and Marcelo Levy, Bolivia

Nutrition Management and Multi-disciplinary Approaches in GIST

Speaker: Berenice Carbajal-López, Fundación GIST México

Fueling GIST Research: Our Community in Action

Speakers: Diana Nieves with three patient advocates

Managing Mental Health After Cancer Diagnosis

Speaker: Sarah Paul, Cancer Care

Clinical Trials 101

Speaker: Dr. Ciara Kelly, Memorial Sloan Cancer Center

Updates from ASCO

Speaker: Dr. Herbert Loong, The Chinese University of Hong Kong

How to Advocate for Yourself/Loved One with GIST

Speakers: Santy DiSabatino with three patient advocates

How to Manage Side Effects of GIST Therapies

Speaker: Dr. Emmeline Academia, Harvard University

GIST Awareness Day: GIST Research Updates

Speakers: Dr. Jason Sicklick, University of California San Diego, Dr. John Glod, NIH Center for Cancer Research, and Dr. Ramesh Bulusu, Cambridge University Hospitals

Updates from CTOS

Speaker: Dr. Herbert Loong, The Chinese University of Hong Kong

Understanding GIST and Desmoids

Speakers: Dr. Jonathan Trent, Sylvester Comprehensive Cancer Center and Dr. Steven Bialick, Sylvester Comprehensive Cancer Center

Matching Biomarker to Biology and Therapy

Speaker: Dr. Jason Sicklick, Moores Cancer Center, US San Diego Health

DATA MANAGEMENT & RESEARCH

This year has been marked by significant achievements and milestones, underscoring our commitment to excellence in data management, research, and collaboration.

Abstracts and Peer Review Publications

This year, we achieved remarkable success in academic publications and presentations. We proudly announce the submission and acceptance of six abstracts, posters, and research publications in reputable journals and conferences. Notably, we are honored to have been published in *Nature Medicine*, one of the most prestigious scientific journals, alongside key GIST leaders. These contributions cover a diverse range of topics, reflecting our dedication to advancing knowledge and research in GIST.

Among our notable publications are studies focusing on innovative data management techniques and their applications. Our research publication emphasizes the importance of robust data management practices in facilitating superior research outcomes, particularly in optimizing survival and increasing the understanding of GIST heterogeneity.

Furthermore, our abstracts submitted to prestigious conferences such as the European Society of Medical Oncology (ESMO) and the Connective Tissue Oncology Society (CTOS) explore various aspects of GIST research, including longitudinal follow-up, recurrence-free survival, and advanced sequencing techniques to characterize tumor heterogeneity. We were honored to be selected for an oral presentation at the CTOS conference, discussing recurrence-free survival in GIST, in a highly competitive session.

Data Management & Patient Registry Enhancement

Aligned with our commitment to advancing research and improving data management practices, we have successfully initiated a project to enhance our existing patient registry database. This project involved implementing updated software and developing innovative tools aimed at streamlining data collection, management, and analysis.



The enhanced data management system will provide patients, caregivers, and researchers with a user-friendly platform to access, follow, and analyze complex datasets. With features such as intuitive data visualization interfaces and advanced analytics capabilities, this project represents a significant step toward optimizing research efficiency, empowering patients, and enabling data-driven decision-making.

The LRG Patient Registry boasts a comprehensive database of over 2700 patients from around the world. Our unwavering dedication to offering support and guidance to all members underscores our mission to ensure no patient faces GIST alone. This commitment serves as the driving force behind all our endeavors.

In the past year, we warmly welcomed 201 new members from diverse corners of the globe such as Japan, Hong Kong, Ireland, Sweden, New Zealand, Brazil and Costa Rica. We continue to expand our reach and provide a sense of community to patient and caregivers affected by GIST, fostering connections and solidarity across borders.



Data Collaborations

Collaboration is at the heart of our research efforts, and this year has witnessed the initiation of several promising partnerships with academic institutions, industry partners, and government agencies. These collaborations aim to leverage collective expertise and resources to address key challenges in data management and research. Noteworthy collaborations include initiatives to explore novel biomarkers in GIST, understanding of SDH covariates, neoadjuvant and adjuvant studies, and forming a consortium with key global leaders to enhance the risk criteria in GIST. These partnerships hold the promise of unlocking new insights and driving innovation in data management and research practices.



In conclusion, the past year has been marked by significant progress and achievements for the Data Management & Research Team. We remain committed to excellence in data management, research, and collaboration, and we look forward to continued success in the years to come.

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