



Annual Report **2022**



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"Stories have to be told  
or they die, and when they die,  
we can't remember who  
we are or why we're here."  
*- Sue Monk Kidd, author*

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In 2022, our theme, "It's Time to Tell the Stories," marked a significant milestone as we celebrated 20 years of non-profit service. Throughout 2022, we embarked on a journey of sharing narratives, videos, and informative webinars, with the aim of illuminating the world about GIST, its research, and the pivotal role played by The Life Raft Group. Our commitment to raising awareness and fostering understanding remains unwavering. Together, we continue to make strides in the battle against GIST, ensuring that no one faces this challenge alone.

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## A MESSAGE FROM OUR EXECUTIVE DIRECTOR



As I reflect upon the milestones and progress, we achieved in 2022, I am humbled and inspired by the LRG team and volunteers who helped make our efforts so successful, especially in the first year of my new leadership role as Executive Director. The sections of this Annual Report bear witness to the dedication, hope, and commitment of our team, our members, and our partners in our mission to empower and support those affected by GIST (Gastrointestinal Stromal Tumor) and other rare diseases.

The past year was filled with challenges as we downsized our office and staff. Yet, it was also a year of remarkable growth and transformation for our small, but mighty team. In 2022, we celebrated our twenty-year anniversary at Life Fest in New Orleans. This was the first time we gathered in person since before covid. The emotions and energy in the room were palpable, hearing from inspiring mentors as well as young adults who were living with GIST for many years. We all walked together in solidarity for our GIST Do It Walk, and it symbolized how our commitment to the GIST community is unwavering.

Our research initiatives continued to pave the way for the importance of patient reported outcomes. Through collaborative efforts with leading institutions, we made strides in understanding the genetic underpinnings of GIST. Our partnerships with academic partners were highlighted at the annual Connective Tissue Oncology Society (CTOS) meeting in Vancouver as we had a poster outlining updates from our patient registry. Additionally, three of four oral presenters during the GIST session shared that their research was in partnership with the Life Raft Group. Our relentless pursuit of knowledge and its translation into actionable results underscore our dedication to making a tangible difference in the lives of those we serve. Advocacy remained at the forefront of our activities, as we tirelessly championed for patient rights, particularly with access to approved GIST therapies around the world. The collective voices of our community grew louder and more influential as we articulated that the needs and concerns of rare cancer patients were heard and addressed.

None of this would have been possible without the generous support of our donors, sponsors, and partners. Your unwavering belief in our mission fuels our determination to continue pushing boundaries and seeking new ways to improve the lives of those we serve. As you read our Annual Report, let us celebrate our achievements, acknowledge our challenges, and renew our resolve to forge ahead. The journey ahead may be challenging, but we are fortified by the spirit of unity and hope that defines The Life Raft Group.

Together, we are charting a course for a brighter future for rare cancer patients everywhere. Thank you for being part of our extraordinary community, and here's to a year of continued growth and impact in the coming year.

*Sara Rothschild*

**Executive Director**

## IMPORTANT HIGHLIGHTS

### FOUNDER & FIRST EXECUTIVE DIRECTOR



**Norman J. Scherzer**

In March of 2022, The LRG experienced a significant transition when Norman J. Scherzer, the Executive Director since the organization's inception in 2002, passed the leadership mantle to Sara Rothschild, a dedicated and longstanding team member. Under Norman's leadership, the organization has achieved remarkable growth, now counting thousands of members globally. Under Norman's stewardship, the organization has raised over \$9 million for GIST research in the US and Europe. Key achievements include the creation of a patient registry with clinical histories from over 2,000 patients across 69 countries, a GIST tumor bank housing over 800 patient tumor samples, one of the earliest databases for GIST therapy side effects, and a thriving community of GIST patient mentors, all patient-led. During this time The Life Raft Group extended a successful support model to assist other rare cancer patient groups, solidifying its commitment to broadening its impact within the rare cancer advocacy landscape.

Norman's legacy is one of extraordinary achievement, marked by unwavering dedication to advancing research, enhancing patient care, and fostering a global community united in the fight against GIST and rare cancers.

## THE LIFE RAFT GROUP BOARD OF DIRECTORS

The past year brought significant transformations to the esteemed Life Raft Group Board of Directors.



**Jerry Cudzil**

After a remarkable 14-year tenure as Board President, Jerry Cudzil made the decision to step down from his leadership role. His exceptional fundraising efforts have left an indelible mark, contributing significantly to the advancement of research, support, and educational initiatives within the LRG. It is with profound respect that we acknowledge Jerry's dedicated commitment, particularly as he devoted his time to honor his late father-in-law, who succumbed to GIST. Jerry's stewardship has been instrumental in navigating the Life Raft Group through the dynamic landscape of rare cancer advocacy.

Jerry's exceptional fundraising endeavors have made invaluable contributions to the research, support, and educational initiatives of the LRG. It is worth noting that Jerry devoted his time to honor the memory of his father-in-law, who tragically succumbed to GIST.

Stepping into this distinguished role, Gary Glasser assumed the presidency of the Board. Gary has been a valued member of the Life Raft Group's Board since 2013, having also held the position of Secretary-Treasurer since 2015. Furthermore, since 2020, Gary has skillfully led the Data Science and Strategy group for Birch Hill Equity Partners, a private equity firm based in Toronto. His introduction to the world of GIST was a personal one, as it stemmed from his late father's diagnosis with this rare disease.

In 2022, we welcomed three new Board members. Patricia Bonda-Swenson, a dedicated member of the LRG since 2007, as she brings a wealth of experience from the Trade Show and Architectural Interior industry. Santy DiSabatino, a former educator and administrator, and an impassioned GIST advocate, also leads as the US Director of the LRG's GIST Mentor Program. Bill Borwegen, a resolute GIST advocate, boasts an extensive background in lobbying for the enactment of laws and regulations aimed at safeguarding the well-being of healthcare and service workers in the face of on-the-job hazards. In addition to these positive transitions, Steve Pontell, Esq., our devoted volunteer counsel, took on the role of Vice President of the Board. Kay Stolzer has assumed the responsibilities of Secretary, and newcomer Santy DiSabatino began his tenure as Treasurer.

Our Board members have been actively engaged in committees that drive transformative change, spearheading fundraising campaigns that significantly augment our financial resources, and participating in meetings that are pivotal to the ongoing success of our organization. In addition to our routine quarterly meetings, a significant half-day session held during Life Fest in July 2022 provided a fertile ground for innovative ideas to flourish and for both new and established members to be invigorated, further solidifying their integral role as contributors to the continued success of our organization.



**Gary Glasser**  
President



**Steve Pontell**  
Vice President



**Kay Stolzer**  
Secretary



**Santy DiSabatino**  
Treasurer



**John Abrams**



**Dr. Monica Anderson**



**Patricia Bonda-Swenson**



**Bill Borwegen**



**Stan Bunn**



**Jim Hughes**



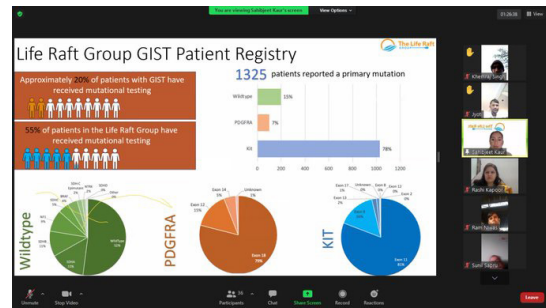
**Teena Petersohn**



**Rodrigo Salas**

## RESEARCH

The Life Raft Group continues to focus on advancing critical research-related topics in the field of GIST. Our central mission centered on promoting mutational testing, an essential element in tailoring effective treatments for all GIST mutations. We diligently advocated for the significance of mutational testing and facilitated access to this crucial diagnostic step, empowering patients to make informed decisions about their healthcare. Our primary goal is to optimize treatment plans, ultimately leading to better patient outcomes.



This commitment extended to building a robust, research-focused Science Team. This team is instrumental in advancing our understanding of GIST and driving innovative research. In addition, we actively supported the Pediatric & SDH-Deficient GIST Consortium, collaborating with global experts in the GIST field to accelerate research progress. We showcased our dedication to research by actively representing our interests at international conferences, publishing papers and posters to share invaluable insights, and expanding our Medical Advisory Board to further enhance our leadership and expertise.

As part of our comprehensive approach, we welcomed over 200 new members to our GIST patient registry. This significant growth enhances the registry's value, offering a diverse and extensive database for researchers, clinicians, and patients. The larger registry equips us to better support research initiatives and, ultimately, to improve the lives of those affected by GIST. Our unwavering commitment to GIST research is resolute, as we advocate for enhanced patient outcomes and push the boundaries of knowledge in the field.

The Patient Registry department was renamed Data Management & Research this year to more fully reflect the duties of this department which includes curation & maintenance of the LRG GIST Patient Registry, GIST research, data analysis, and as a touchpoint for new members and GISTers in need of consultation for treatments, side effects, and clinical trials.



In 2022 we continued our *Tissue Testing Project* with the goal of identifying patients who haven't received testing for biomarkers, by creating awareness through videos, social media, and surveys of our membership.

In April, the Data Management & Research team held a *Virtual Tumor Board* featuring four cases presented from all over the world, further emphasizing the importance of virtual reviews. These cases highlighted new characteristics of GIST and cases that were atypical. Global reach is one of LRG's main priorities and advocating for access of care, treatment and affordable medications. With the LRG's relationships with medical experts and institutions in many countries, patients and doctors who are out of options and are unsure of next steps can tap into

our large community of the world's leading GIST experts who are part of our Virtual Tumor Boards and are willing to share their suggestions. This forum also allows the LRG to be the moderator, bringing forth challenging and rare cases to experts, calling attention to new characteristics of GIST and working together with GIST experts to accelerate research and build novel treatment strategies.

The LRG team published, ***“Barriers to mutational testing in patients with gastrointestinal stromal tumors (GIST) - a survey of Life Raft Group members”*** which focused on the incidence of mutational testing among our members. The study was initiated due to the observed rates of mutational testing among the general GIST patient population which is about 26.7% in the U.S. despite standard guideline recommendations from agencies such as the National Comprehensive Cancer Network (NCCN) and College of American Pathologists (CAP).

The Life Raft Group collaborated on a study published in August entitled, ***“Undetected KIT and PDGFRA mutations: an under-recognised cause of gastrointestinal stromal tumours (GISTs) incorrectly classified as wild-type,”*** with Dr. Maria Pantaleo, Annalisa Astolfi, Anthony Gill, and Brian Rubin. This team of experts worked together in drafting this important position paper to increase awareness on this critical issue.

The Data Management & Research team launched two new Facebook Support Groups with a specialized focus for patients and their caregivers; designed to provide a safe forum to discuss specific concerns in a closed environment. One group focused on discussing issues around ripretinib (Qinlock) and the other on patients currently on or considering enrolling in the Cogent trial for CGT9486.

The Life Raft Group had a presence at several important conferences around the world including ASCO (American Society of Clinical Oncology), the Precision Medicine Symposium, and CTOS (The Connective Tissue Oncology Society), where The LRG presented a poster entitled, ***“Phase I Results from a Multi-Phase Comprehensive Genomic Sequencing Tumor Study in Gastrointestinal Stromal Tumor,”*** and contributed data for a presentation called, ***“GIST & Other Sarcomas with Actionable Targets,”*** presented by the team at The Royal Marsden NHS Foundation Trust, London, England.



As a founding member of the National Institutes of Health’s Pediatric & Wildtype GIST Clinic, The LRG continues to participate at this annual event which connects us with GIST patients so that we can support patients with SDH through their treatment journey. Concerning SDH, the Pediatric & SDH-Deficient GIST Consortium remains at the forefront of SDH research and collaborations to develop to new therapies for this rare GIST subset.

## THE LRG MEDICAL ADVISORY BOARD

The goal of The LRG Medical Advisory Board is to share scientific and research expertise to provide strategic direction on LRG initiatives to ensure the survival and well-being of GIST patients.

The Board is comprised of experts from leading academic and medical institutions around the world: Dr. Michael Heinrich, OHSU Knight Cancer Institute; Dr. Sameer Rastogi, All India Institute of Medical Sciences; Dr. Peter Reichardt, Helios Klinikum Berlin-Buch; Dr. Gary Schwartz, Case Comprehensive Cancer Center; Dr. César Serrano, Vall d’Hebron Institute of Oncology; Dr. Jason Sicklick, UCSD Moores Cancer Center; Dr. Jonathan Trent, Sylvester Comprehensive Cancer Center.

Dr. Neeta Somaiah joined our esteemed team of experts in 2022. She is the Associate Professor of Sarcoma Medical Oncology and serves as the Deputy Chair of Sarcoma Medical Oncology at The University of Texas MD Anderson Cancer Center in Houston, Texas. Her primary clinical and research focus is soft tissue sarcomas, specifically liposarcomas and GIST (gastrointestinal stromal tumors).



**Michael C. Heinrich, MD**  
OHSU  
Knight Cancer Institute



**Sameer Rastogi, MD**  
All India Institute of  
Medical Sciences



**Peter Reichardt, MD**  
Helios Klinikum  
Berlin-Buch



**Gary Schwartz, MD**  
Case Comprehensive  
Cancer Center



**César Serrano García, MD**  
Vall d’Hebron  
Institute of Oncology



**Jason Sicklick, MD**  
UCSD  
Moores Cancer  
Center



**Neeta Somaiah, MD**  
MD Anderson  
Cancer Center



**Jonathan Trent, MD**  
Sylvester  
Comprehensive  
Cancer Center



## OUTREACH & SUPPORT

The Outreach & Engagement team functions as the foundation for building support systems for patients and caregivers through facilitating support groups, a mentoring program, and educational days of learning throughout the US. O&E also trains mentors, facilitates fundraising events & GIST Do It Walks, promotes GIST Awareness Day, and creates life-changing events for patients & caregivers with our biennial Life Fest event.

This year we welcomed 209 new members to our LRG community.

### STATE AND GLOBAL REPRESENTATIVES

As of December 2022, The Life Raft Group State and Global representatives were serving in 21 states and 51 countries, with support groups operating in local areas in-person and online.

Of note, long-term survivor, support group leader & advocate, Dina Wiley, an integral member of our LRG family embodying all the best qualities of a patient advocate, stepped down from her post as SoCal representative. Dina became our SoCal state representative in 2011 and has been instrumental in providing support for the newly diagnosed as well as aiding in the planning and execution of GDOLs and Life Fest events. Dina will always remain a valued member of our GIST family.



### MONTHLY SUPPORT GROUPS

Our commitment to patients and caregivers extends far beyond discussing medical treatment and analyzing data for research. Facing a serious illness can be an emotional and challenging journey, and we believe that a strong support system is essential. To fulfill this commitment, our US and global representatives organize and host regular support group meetings for patients and caregivers.

These meetings provide a platform for patients and caregivers worldwide to connect with others facing similar challenges. Building a sense of community helps individuals realize they are not alone in their struggles.

*When I think of The Life Raft support group, words to describe how it has impacted my life by participating include: educational; motivational; hope; caring; sharing; informative; and relaxing. 'S' is a wonderful coordinator and genuinely concerned about each participant. He makes sure that we all have a chance to share updates about our journey. I enjoy when there are guest speakers to discuss different topics; video and reading references for follow up after discussions. After my diagnosis and surgery I was advised to seek therapy to help me better cope/understand living with cancer, side effects from Gleevec, etc...I tried, unsuccessfully, two or three therapists. I didn't feel any connection. There didn't appear to be any true concern or interest. Along came Life Raft....I appreciate The Life Raft Group for reaching out to me. I have met some very interesting and authentic people willing to share without inhibitions. Their contributions are sincere, real experiences. We all know the GIST journey continues to be challenging but I am thankful. I hope to be more involved in the group as time goes on and I become more informed, able to assist and give back. I would absolutely recommend the group (and I have) without hesitation. - Susan Franze*

## THE GIST MENTOR PROGRAM

The Life Raft Group's GIST Mentor Program is dedicated to providing essential support to individuals with GIST and their loved ones as they navigate the challenges of diagnosis and treatment. This program serves as a guiding light, offering patients and caregivers the tools to advocate for themselves and extending a comforting hand of emotional support throughout their GIST journey. Our LRG GIST Mentors, comprised of survivors and caregivers, play a vital role by offering understanding and empathy, reassuring patients and their support networks that they are not alone in their GIST journey.

Launched in 2019, the GIST Mentor Program has expanded significantly, with 22 mentors and 307 mentees in the United States in 2022, skillfully facilitated by Santy DiSabatino, a dedicated patient advocate and LRG Board Member, along with our international program director Piga Fernández, who also serves as our Global Coordinator. The program's remarkable growth, from its inception with seven mentor trainees in 2019, is a testament to its significance, and we are committed to expanding our mentorship network in 2023 to accommodate the growing waiting list of patients and caregivers seeking mentorship.

*It feels so good having all these strangers in my corner with me.* - Michelle Tobias

*Thank you for the information. I have already had an encouraging chat with my mentor. I am so grateful.* - Dr. mOe Anderson

*My Mentor has contacted me, and we will be talking soon. Again, thank you! What a valuable program this is.* - Susy Clough

*"Mentoring is an interesting privilege, as you support another GISTer through a new and sometimes confusing experience, you realize how much it is helping you."* - Karen Meyer

## GIST DO IT WALK, VERONA PARK, NJ

The GIST Do It Walk NJ was held April 9th. This annual walk was established in honor of GISTer Ted Wolf who passed away in 2018. In memory of Ted, various members of the Wolf Family walked with us simultaneously in separate parts of the country to add to the comradery, and to honor Ted with our efforts and donations in his name.

## GIST AWARENESS DAY - JULY 13TH

GIST Awareness Day (GAD) is a defining moment in our annual calendar, where our aim is to demystify GIST, making knowledge about this rare disease more widespread. As a community - patients, caregivers, medical professionals & researchers, pharma, and donors - spread the word throughout social media that we are supporting GIST patients and GIST research.



Coinciding with the 20th anniversary of The Life Raft Group as a nonprofit, our emphasis was on patient and caregiver stories that reaffirmed the power of community. We hosted an SDH-deficient GIST-focused webinar, presented by Dr. John Glod, NIH, and featured SDH-deficient GIST patient Lleyton Schlesky.

Across the globe, there were various & diverse interpretations of the GAD theme, as well as many local meetings, webinars and other educational events from patients & caregivers, patient advocacy groups, pharma, clinicians, researchers, family & friends.

## LIFE FEST 2022

In July of 2022, our LRG community came together for Life Fest after a four-year hiatus due to the Covid pandemic. This long-awaited event in New Orleans was marked by the dedication of our staff, volunteers, GIST Mentors, board members, and participants and the celebration of our 20th anniversary. Attendees included 130 patients, caregivers, LRG staff, clinicians and medical professionals.

The Life Fest Scholarship Fund, made possible by our Board of Directors and donors, enabled 10 families to attend the conference.

*It was my first Life Fest but it won't be my last. I loved everything about it! Loved the GIST specialists with all of their new information and wonderful ideas for treatment. Life Raft staff was wonderful! Helpful and cheerful and well organized! Thanks for all you do!*

- Margaret McInteer

*The thanks belongs to you and the LRG team. You all are a great collection of selfless people who compassionately care for folks that have great need. You listened to Santy's heart and supported his vision. You treat us mentors like gold and we have learned to have great love for each other. Thank you for each time that you have brought us together. Thank you for caring and sharing part of your life with who Christ called "the least of these". Much peace.*

- Rob Taylor

*Thank you so much for your part in making another Life Fest a wonderful, reassuring and gratifying experience. You, Diana, and the rest of the Life Raft staff are truly amazing, loyal and dedicated souls who have provided such a wealth of information and education for all GISTer's and our Caregivers. I feel so fortunate to be within the arms of the LRG guidance. THANK YOU AND TO ALL THE STAFF! Seeing past fellow GISTer's and meeting all of you fellow Mentors held special meaning for me. Bless us all and as always, Self Advocate, Self Advocate, Self Advocate!* - Jon P. Treder



## GIST MOSAIC AT LIFE FEST

Cogent Biosciences, Inc. partnered with the LRG to create a GIST Mosaic to raise awareness for GIST, promote hope, and to honor our patient/caregiver/advocate community. Cogent collected over 500 photos for this memorable collage.



## 2022 FUNDRAISING EVENTS

### G.E.M. PROGRAM

The LRG's Give Every Month (GEM) Donors provide regular gifts to help ensure a consistent and steady stream of support to GIST patients and their families. In 2022, 30 GEMs were a part of the program and we are grateful for this consistent and continual source of funding.

### SPRING 20-20 CAMPAIGN

The Spring 20-20 Fundraising Challenge - As part of our 2022 "It's Time to Tell the Stories" theme, we committed to raising \$20,000 by Life Fest New Orleans (July 29-31st) with a 20-20 Challenge in honor of our 20 years as a non-profit organization.

### HOLIDAY CAMPAIGN

Our Good News Holiday Campaign was the culmination of our year of "Time to Tell the Stories 2022." We raised \$38,050.75 celebrating our global impact, contributions towards GIST research and support services.

### NIGHT TO FIGHT CANCER

Jerry Cudzil's annual Night to Fight Cancer fundraiser returned to NYC after three years online due to the pandemic. Hosted by Jerry and colleague Matthew Knopman, the event once again took place at Midtown Loft. This event is historically our largest in-person fundraiser for the year, and we are thankful to the donation by Lyon Carter III and event sponsors Bank of America, Capital Markets, Credit Suisse, Jefferies, Tradeweb, Trumid and Morgan Stanley.



The tournament winners were: 1st Place: Jeff Leach, 2nd Place: Michael DiSanto, and 3rd Place: Michael Lee. Thank you to volunteers Teena Petersohn, Kathrena Aljallad, and Jasleen Kaur!

### WATER OF LIFE

The 5th Water of Life Fall Event (WOLF) on November 2nd was a resounding success, bringing together whisky enthusiasts and top industry representatives at Keen's Chophouse and the Carnegie Club. This annual charity event, hosted by Dr. Matthew Lurin, raised nearly \$12,000 for The Life Raft Group, making it one of our most memorable WOL gatherings.

The Life Raft Group wants to also acknowledge our gratefulness for the countless patients & caregivers and friends & family who have hosted personal fundraising events and Facebook fundraisers this year.

## Information, Education & Advocacy

We continue to see that empowered and educated patients have higher survival rates, and that by raising awareness and providing information about GIST, we help patient to survive and thrive.

Educational events are one of the ways that we share information and education about GIST, treatments, side effects and trials. One of our core values is to educate and empower patients to take a larger role in their care.

In the past year, we produced 12 webinars:

***The Value of Biomarker Testing: Case Studies Across Multiple Institutions*** (Jan 6) – Dr. Prapassorn Thirasastr, MD Anderson Cancer Center, Dr. Steven Bialick, Sylvester Comprehensive Cancer Center, and Dr. Dixon Dorand, Vanderbilt University Medical Center.

***LRG Conversations: Let's Get to the GIST of It - Qinlock*** (February 5) – hosted by the Data Management & Research Team, The Life Raft Group.

***An Interactive Q&A with SDH Families for Rare Disease Day on February 28*** – Sahibjeet Kaur, Director Data Management & Research, The Life Raft Group with two patient advocates.

***Be An Informed Patient: Navigating Survivorship Care*** (February 22) – Dr. Crystal Denlinger, NCCN, and Dottie Shead, MS, NCCN Patient Information & Operations.

***Be An Informed Patient: Navigating GIST NCCN Guidelines*** (April 13) – Dr. Margaret von Mehren, Fox Chase Cancer Center, and Denisse Montoya, Senior Director, Data Management & Research, The Life Raft Group.

***The Effects of Nutrition and the Gut Microbiome in GIST Patients*** (May 4) – Berenice Carbajál-López, MS Health Sciences & PhD candidate, Fundación GIST México.

***Updates from ASCO 2022*** (June 15) – Dr. Andrew J. Wagner, Dana-Farber Cancer Institute, and Dr. Herbert Loong, The Chinese University of Hong Kong

***Managing Medical Bills*** (June 29) – Melissa Salamon, Triage Cancer

***GIST Awareness Day Webinar: SDH Updates & Stories for GIST Awareness Day*** (July 13) – Dr. John Glod, NCI, Pediatric Oncology Branch, NIH, and Leyton Schelesky, Patient Advocate

***The Importance of Biomarker Testing*** (August 12) – Dr. Michael Wagner, Fred Hutchinson Cancer Research Center, University of Washington

***The Emerging Role of Circulating Tumor DNA in GIST*** (October 15) – Dr. Steven Bialick, Sylvester Comprehensive Cancer Center, University of Miami Health

***Surgical Considerations for GIST*** (November 8) with Dr. Andrew Blakely, NCI, Center



### 2022 Webcast sponsors were:

Blueprint Medicines, Deciphera, Genentech, and Novartis

## GIST DAYS OF LEARNING



A GIST Day of Learning, or GDOL, is a free one-day event to help patients and caregivers learn more about this rare cancer, find support, and enhance their knowledge base to help them navigate their cancer journey. Typical sessions focus on topics such as GIST treatment updates, managing side effects, and multi-disciplinary care and include question & answer time and panel discussions with experts.

- GDOL Tennessee was held on February 25th, virtually, in collaboration with Vanderbilt University Health.
- GDOL Washington DC was held on April 27th, virtually, in collaboration with MedStar Georgetown University Hospital and MedStar Washington Hospital Center.
- GDOL San Diego was held in-person September 24th with UCSD Moores Cancer Center.
- GDOL Miami was held in-person on November 4th at the University of Miami Miller School of Medicine in collaboration with Sylvester Comprehensive Cancer Center.
- GDOL North Carolina was held virtually on March 24 in collaboration with Duke Cancer Center.

### **2022 GDOL Sponsors were:**

Blueprint Medicines, Cogent Biosciences, Deciphera, Genentech, Novartis and Pfizer.

## ADVOCACY

The Life Raft Group continues to collaborate with patient advocacy organizations to help patients with GIST globally. Our Global Relations Coordinator, Piga Fernández, who also serves as our International GIST Mentor Director oversees a team of GIST Mentors who work with patients & caregivers across the continents as well as organizing and advising our global liaisons in over 60 countries and coordinating foreign language translations of webinars and important patient information sheets.

We continue our efforts to advocate for all newly diagnosed patients to receive biomarker testing and are committed to also champion that effort into the future. In our own GIST Patient Registry, the number of patients who have received biomarker testing has increased to over 50%.

We continue to be involved with NORD (National Organization for Rare Disorders) attending their annual Summit, as well as promoting Rare Disease Day and Rare Cancer Day, and participating in the Rare Cancer Coalition and Rare Disease Council and presenting a profile of The Life Raft Group & GIST, and our services and challenges, for the virtual NJ Rare Disease Day.

The LRG remains part of the Milken Institute's Faster Cures, as one of the original members of TRAIN (The Acceleration and Innovation Network), the Sarcoma Coalition, the Patient Advocacy Board of the Herbert Irving Comprehensive Cancer Center, SPAGN, New Horizons, Fundación GIST Mexico and Chile, and OVAC.

# DONORS

## Funding Partners

### \$100,000 - \$175,000

Daiichi Sanko, Inc.  
Deciphera Pharmaceuticals

### \$75,000 - \$90,000

Blueprint Medicines  
Cogent Biosciences, Inc.

### \$20,000 - \$60,000

AmMax Bio, Inc.  
Genentech  
LabCorp Drug Development, Inc.  
Novartis Oncology  
Theseus Pharmaceuticals

### up to \$5,000

Guardant Health  
Foundation Medicine Inc.  
Horizon Therapeutics  
ICG Life Sciences  
IDRx, Incorporated  
Just Worldwide  
SynOx Therapeutics

### \$200,000 - \$300,000

BST Consultants

### \$20,000 - \$30,000

Richard Becker  
Palermo-Ravich Family  
Foundation

### \$10,000 - \$19,000

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Credit Suisse  
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Jim & Margi Hughes  
Teena Petersohn  
Ira & Kay Stolzer  
Tradeweb Markets LLC  
Trumid Financial LLC

### \$5,000 - \$9,999

Iris Berke  
Benji Cheung  
Design America  
Thomas Green  
Idea Village Products Corp  
The Knopman Family Charitable Fund  
Morgan Stanley  
Lucina Stricker  
Alice Sulkowski  
Vinyl Destination

### \$1,000 - \$4,999

John Abrams  
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The Benevity Community  
Impact Fund  
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Chiwoniso Kaitano  
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Thomas Keller  
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Alice Kondis  
Stelios Koutsoumbelis  
Milan Kovac  
Adam Levy  
Pam London  
Lisa Lowry  
Ellen MacDonald  
Chet Malhotra  
Hannah Marcus  
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Camille Mayotte  
Patrick McCarthy  
Margaret McInteer

Carol Morris  
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Giving Fund  
Alexander Robinson  
Ellen Rosenthal  
Anand Sankaranarayanan  
Jason Schechter  
Schwab Charitable Fund  
Giacomo Selloni  
Robert Sholiton  
Eric Smyrl  
James Snyder  
Deborah Spear  
Andrew Stalbow  
Morgan Stanley

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Wes & Jacob Treder  
Richard's Urquhart  
Mark Vieha  
James Walton  
Jill Whitney  
Dina Wiley  
Wendy Williams  
Martha Zielinski

### \$500 - \$999

Behrooz Akbarnia  
Erick Ammons  
Olof Asbrink  
Alex Atallah  
Ryan Atkinson  
Larry Barclay  
Richard Bellofatto  
Jules Bender  
Sergey Bessmertny  
Boeing Company  
Drew Brantley  
Sally Susman  
& Robin Canter  
Brian Carr  
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Lyon Carter III  
JP Morgan Chase  
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Vanguard Charitable  
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Michael DiSanto  
Roy Dyer  
Alex Fass  
Daniel Fleiner  
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### What Do We Do?

**RESEARCH**

- Host clinical trial matching service (gisttrials.org).
- Contributed to over **100** publications.
- Published **26** studies/posters in past five years
- Directly supported the success of at least **10** GIST-relevant clinical trials.
- Establish new clinical trial options for rare subsets of GIST.
- Make connections between novel published concepts & teams who accelerate a cure.
- Facilitate sharing of complex GIST cases among **75+** global GIST experts in order for collaboration & consultation about treatment and care.

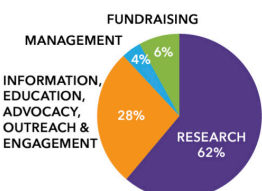
**PROGRAMS**

- Consult with over **50+** patient per week.
- Facilitate a **GIST Mentor Program** serving over 300 patients & caregivers globally.
- Host **5** U.S. **GIST Days of Learning** yearly at major cancer centers.
- Conduct monthly educational webinars online.
- Host the biennial **Life Fest**, our premier educational & support event for patient & caregivers.
- Connecting **7,500+** patients & caregivers through private social media groups & private chat forums.

**GENERAL**

- Directly support patients navigating complicated health insurance and treatment access issues.
- Managing over **1,000** emails, calls, and texts per week supporting the GIST community.
- Gifting care packages to those who need extra support & love.
- Working with over **150** volunteers who help us carry out our programs and services.

### Where Does Your Money Go?



OVER **\$15M** INVESTED IN RESEARCH


**Quick Facts**

ABOUT **5000** PEOPLE EACH YEAR ARE DIAGNOSED WITH GIST IN THE US

**2642** PATIENT REGISTRY MEMBERS (AS OF 7/2023)

OVER **100** SUPPORT GROUPS HELD PER YEAR

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