



## December 2022

Our Good News Holiday Campaign is the culmination of our year of "Time to Tell the Stories 2022." In this series, we celebrate the connections, the celebrations, the events and milestones that we've been privileged to be a part of this year. Our 20th anniversary year is winding down and we are wrapping it up by spreading good news & gratitude throughout the season. Your financial donations and selfless volunteerism are what enable us to continue providing vital services to our GIST community.



# A Word from Our Executive Director

As we come to the end of 2022, I would like to take a moment to reflect on the past year, and to look forward to the potential of the coming year for our GIST community. This year, we celebrated our 20-year anniversary as a non-profit with the theme "It's Time to Tell the Stories" by sharing the incredible journeys of our patients and caregivers, and by reflecting back on all we have achieved over the years.

In this year of challenges and transitions, I became the Executive Director of The Life Raft Group, and through the support of our staff, Board of Directors, Medical and GIST communities, began to formulate our vision for the future. The profile of the Life Raft Group has changed since March 2022. Although maintaining true to our mission and vision and always keeping the patient at the heart of everything we do, we took steps to both elevate the profile of the LRG, and to expand our impact on GIST research. We expanded support services and strengthened both our Board of Directors and our Medical Advisory Board.

After a listening tour, which included staff, Board members, and GIST Mentors, a strategic vision for the LRG going forward was created. Two of the most important goals were:

- 1. Never lose focus from the patients and the personalized contact we have with our community. Support and Education should continue to be an important mainstay of our organization.
- 2. Create a stronger scientific/research direction for the organization by utilizing an expanded LRG Science Team as well as staff/consultants/volunteers

And we are off to a great start. To mention just a few highlights of our 2022 accomplishments:

- Expanded our Board of Directors
- Added new Medical Advisory Board members
- Expanded collaborations with companies such as Labcorp, Cogent, Theseus, IDRx and Medscape
- Presented 12 educational webinars, and held five GDOLs
- Expanded our social media profile with more engagement with medical professionals
- Increased support groups
- Expanded numbers for Mentor program with 30 mentors and 259 mentees
- Presented a Poster at CTOS and was part of a collaborative presentation
- Supported translation research with a donation to Jason Sicklick's UCSD research lab
- Expanded LRG Science Team
- Collaborated with several researchers on projects
- Continued Tissue Testing Initiative, working on increasing precision medicine awareness to patients and physicians by offering free mutational testing
- Published five peer-reviewed research articles
- Invited to speak at national and international conferences and meetings.
- First in-person Life Fest since pandemic attended by 130.

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- Hosted first in-person Night to Fight Cancer event since covid with 134 participants
- Developed the International GIST Mentors Program
- Continued use of Surveillance Team to aid international patients

And these are only a few of many accomplishments, which we would not have been able to do without your support, through donations, participation in our events and exceptional volunteer efforts. I am humbled by the dedication of this community and am honored to be heading up our efforts as we move together into 2023.

*Won't you join us as we set our Life Raft once again into uncharted waters, with the goal of coming ashore to a place where GIST patients can survive and thrive?*

- Sara Rothschild

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



[bit.ly/LRG-GoodNews](https://bit.ly/LRG-GoodNews)



INCEPTION DATE OF PROGRAM **JUNE 2019**

# OF MENTORS @ INCEPTION **8**

CURRENT TOTAL NUMBER OF MENTORS **30**

CURRENT TOTAL NUMBER OF MENTEES **259**

**PATIENTS 216**  
**CAREGIVERS 43**

## GLOBAL REACH

- |           |              |             |
|-----------|--------------|-------------|
| 1. USA    | 4. SINGAPORE | 8. UKRAINE* |
| 2. CHILE  | 5. AUSTRIA   |             |
| 3. CANADA | 6. KENYA     |             |
|           | 7. INDIA     |             |

\*Not an official mentor but assists with patients in the country/region.

IF YOU ARE INTERESTED IN BECOMING A MENTOR OR BEING MENTORED, PLEASE CONTACT DIANA NIEVES: [dnieves@liferaftgroup.org](mailto:dnieves@liferaftgroup.org)



# Annual NORD Breakthrough Summit Tackles a Diversity of Rare Disease Issues

By Carolyn Tordella  
Director, Communications

I was fortunate to be able attend the National Organization for Rare Disorders Rare Diseases and Orphan Products Breakthrough Summit on Oct. 17-18, in-person, in Washington, DC, via a full scholarship. During this highly anticipated annual conference, expert rare disease leaders covered critical topics and the life-changing experiences of millions of Americans impacted by rare disease.

Pre-conference, on Sunday, over 100 participants, all from NORD member organizations, gathered to share their organization’s story and were welcomed by Director of Membership Debbie Drell and NORD’s President & CEO Peter Saltonstall. Both expressed gratitude that we were able to gather in person this year after a two-year hiatus during which these meetings were held virtually. The 2022 Summit was featured as a hybrid event and participants could view selected presentations via Zoom.

The conference officially opened Monday morning with a greeting to the general audience by Mr. Saltonstall, and then proceeded with three patient/caregiver testimonies in a segment entitled ‘Finding Our Community.’ Brittany Clayborne (Peripartum Cardiomyopathy and Post-Transplant Lymphoproliferative Disorder),



Nakishka Isom (Living with Holt-Oram Syndrome), and Annie Papik (MTHFS Gene Mutation) shared their personal journey into patient advocacy. Their stories stressed the value of helping children live with their differences, getting help with the emotional burden of living with a rare disease, and having the stories of rare disease patients told in all the spaces of rare disease including clinical trial prep and when guidelines are being established.

US FDA Commissioner Dr. Robert Califf followed this presentation reiterating the FDA’s commitment to faster drug approval for rare disease treatments and devices while maintaining high scientific and evidentiary standards, sharing that 50 novel drugs were approved in 2021. He expressed high regard for patient input on clinical trial designs, the significance of real world data, and the critical nature of biomarker development. He shared updates on the joint project funded the FDA, and implemented by the Critical Path Institute and NORD called RDCA-DAP (Rare Disease Cures Accelerator-Data and Analytics Platform) which has continued to make significant progress and is evolving as the platform grows. RDCA-DAP promotes the sharing of existing patient-level data and encourages

the standardization of new data collection. RDCA-DAP houses integrated patient-level data from diverse sources, including clinical trials, longitudinal observational studies, patient registries and real-world data (e.g. electronic health records) across a multitude of rare diseases.



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After the Commissioner’s presentation, participants spread out for meetings that included topics such as Advancing Global Access to Diagnosis, Medicines & Care, Strategies for Enhancing Diversity, Equity and Inclusion in Rare Disease Research, an NIH Town Hall Meeting, and several other sessions focusing topics such as gene therapy, and newborn screening,

Many breakout sessions and lunch and learn sessions were available to participants, and for the LRG, I attended a session on Mental Health & Rare Cancers, moderated by our Rare Cancer Coalition Co-Chairs, John Hopper (Fibrolamellar Caner Foundation) and Jim Palma (TargetCancer Foundation). Panelists shared that we need to intentionally make space to talk about mental health and normalize the conversations around mental health. Also stressed was the need to identify what are normal reactions to a cancer diagnosis versus a clinical mental health issue, and actually starting conversations about mental health before the need arises for these services.

Other sessions that held value for the LRG community were discussions about Patient Registries and the value that we give back to patients through side effects reporting, and leveraging data for clinical trials. The value and use of real world evidence and real world data was discussed in several sessions and provided many points for discussion in reference to patient registry data. And near the end of the conference I was able to participate in a discussion about hybrid events and fundraising, which raised a lot of good ideas for 2023. The conference ended with a fireside chat with FDA Center Directors as they talked about their centers’ current focus.

The NORD Breakthrough Summit is held each fall and welcomes patients, caregivers, medical and healthcare professionals and patient advocacy organizations. More information about the Summit can be found at:

<https://rarediseases.org/>

## Two Simple, but Impactful Ways to Support the LRG



1

### 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 it in.

### B. It's a consistent source of funding for us.

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

**Want to become a GEM?**

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

2

Remember to use **amazon smile** and designate the Life Raft Group as your charity.

### A. Set it and forget it.

Pennies add up quickly! Go to [smile.amazon.com](https://smile.amazon.com) for desktop setup. On your phone, go the Amazon mobile app and select Amazon Smile in Settings and select the Life Raft Group as your designated charity..



## GDOLs

By Laura Occhiuzzi, Deputy Executive Director and Diana Nieves, Senior Director, Outreach & Engagement

### GIST Days of Learning: Opportunities to Grow

Our most recent GIST Days of Learning (GDOLs) were in-person again, as Deputy Director, Laura Occhiuzzi and Senior Director of Outreach and Engagement Diana Nieves traveled to San Diego and Miami to meet with GIST experts and members of our community.

A 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.

In September, Laura and Diana attended a dinner at Season 52 restaurant that was hosted by Moores Cancer Center at UC San Diego, site of the GDOL. Joined by SoCal Leader Dina Wiley and her husband Sam and other patients and caregivers and the presenters, it was an opportunity to socialize before the busy day ahead.

Sixty patients and caregivers participated in the GDOL on Saturday, September 24th at the beautiful Moores Cancer Center campus. There were some long-time members and some new ones, who experienced all that a GDOL has to offer. The gorgeous sunny day began with a GIST Do It Walk around the beautiful grounds of the institution. **Presentations included:**

- GIST 101 by Paul Fanta, MD
- SDH-deficient GIST Update: Bench to Bedside SDH-deficient GIST Research by Jason Sicklick, MD, Temozolomide Trial Update for SDH-Deficient GIST by Adam Burgoyne, MD, PhD and Selective Internal Radiation Therapy (SIRT) for SDH-Deficient GIST Liver Metastases by Zach Berman, MD
- Fluorescence-Guided Cancer Surgery by Michael Bouvet, MD
- Current and Emerging Clinical Trials for GIST by Michael Heinrich, MD
- Personalized Precision Medicine and the N-of-One Approach to Cancer Therapy by Jason Sicklick, MD
- Supportive Oncology Panel with Kathryn Winters, MD discussing Symptom Management and Kristine Zournas, RD discussing Nutrition.

A support group was led by Dina Wiley, PhD, Southern California State Leader.

One of the highlights of the GDOL was the discussion of how to support research and included the presentation of a check for \$25,000 to Jason Sicklick from the LRG to support his research lab.

Laura commented, "We are always so grateful to our medical community who give of their time on weekends to present at our GDOLs. I walk away from these weekends with a renewed sense of optimism. Thank you to the staff of UCSD for helping us organize the event. We couldn't have done this without them."

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In the evaluation forms, participants strongly agreed that they have a greater understanding of GIST, treatments, and surgical options after having participated in this GDOL.

Also an opportunity for fundraising efforts, over \$5K in individual donations were raised, with one member joining our GEMs program. On the road again in November, Laura and Diana next coordinated a GDOL at the University of Miami Miller School of Medicine.

Held at the Don Soffer Clinical Research Center Room: Gordon Center for Simulation

and Innovation in Medical Education, University of Miami Miller School of Medicine on Saturday, November 5th. 45 people registered for this in-person event.

One of the most positive aspects of a GDOL is that it provides an intimate gathering where patients and their caregivers are able to ask all of their questions and have them answered by GIST experts, in this case, Dr. Jonathan Trent and his team. LRG GIST Mentor Carolyn Dewalt was onsite to answer questions about the GIST Mentor program and Florida State Leader Jacklyn Vanderpol talked about the Florida support group held monthly.

On Friday, November 4, a Second Opinion Clinic was held by Dr. Trent and his staff. Saturday's agenda began with a GIST Do It Walk in the beautiful Florida sunshine. After opening remarks by Laura Occhiuzzi and Dr. Trent, the day was filled with informative presentations including:

- Overview of GIST and Its Medical Management - Emily Jonczak, MD
- Surgical Management of GIST - Alan Livingstone, MD and Julie Grossman, MD
- Understanding Pathology and the Role of Mutational Testing - Andrew Rosenberg, MD and Liz Montgomery, MD
- What are the Best Ways to Radiographically Measure GIST? - Francesco Alessandrino, MD
- Psychosocial Implications of GIST - Lisa Marie Merheb, MSW, LCSW
- How Can We Accelerate a Cure - Jonathan Trent, MD
- Side Effect Management - Morgan Mount, APRN, Solange Sierra, MSN, APRN, FNP-B, Gina D'Amato, MD

There was also a Q&A with Dr. Trent's Team.

How could you go wrong attending a GDOL with some of the top specialists in the country? Thank you to the staff and presenters of Sylvester Cancer Center for spending the weekend with us. We couldn't have done this without your help. Thanks go out to our sponsors, who make these events possible: Blueprint Medicines, Cogent Biosciences, Deciphera, Genentech, IDRx, and Novartis.

If you haven't attended an in-person GDOL, check our Events calendar for upcoming opportunities or contact Diana Nieves: [dnieves@liferaftgroup.org](mailto:dnieves@liferaftgroup.org)



CTOS Sheds New Light on #GISTResearch

Executive Director Sara Rothschild and Senior Director of Data Management & Research, Denisse Montoya recently attended the CTOS (Connective Tissue Oncology Society) Annual Meeting in Vancouver, British Columbia.

CTOS is an international group comprised of physicians and scientists with a primary interest in the tumors of connective tissues. The goal of the society is to advance the care of patients with connective tissue tumors and to increase knowledge of all aspects of the biology of these tumors, including basic and clinical research.

The meeting is an opportunity to learn about the most recent research in GIST and other cancers, and a valuable setting for forging collaborative research relationships.

It was both exciting and encouraging that the meeting included a number of GIST presentations and posters holding promise for new treatment strategies. Although understanding that there is much to be accomplished, we are optimistic for future progress.

The Life Raft Group presented an original research poster: *Phase I Results from A Multi-Phase Comprehensive Genomic Sequencing Tumor Study In Gastrointestinal Stromal Tumor Patients* and was also part of research presented by Andrea Napolitano, MD, PhD et al, *A Novel Prognostication System For Patients With High-Risk KIT Exon 9-Mutated Gastrointestinal Stromal Tumour Receiving Adjuvant Imatinib*. This study was presented during the GIST session where The Life Raft Group received honorable mention of their collaboration and support. Acknowledgement also came from Dr. Xiaolan Feng during her presentation *Refining Prognosis in Localized GIST: Clinical Significance of PTEN*, and was also recognized by Joanna Pryzbyl, PhD in the presentation on *Multi-omic Integrative*



Profiling of miniGISTs and Clinically Relevant GISTs Throughout Progression.

Sara and Denisse had ample opportunity to network with leading GIST specialists and researchers, as well as with pharmaceutical companies working on new and innovative treatments for GIST.

According to Sara: “Denisse Montoya and I returned from a global sarcoma medical conference called CTOS. This was the first time the global sarcoma community met in person since 2019.

The Life Raft Group was honored to have a poster featured on our biomarker testing initiative. We were pleasantly surprised that 3 of the 4 on-stage live GIST presentations acknowledged the Life Raft Group’s involvement in advancing their research in the field. This highlighted our organization as a collaborative partner.

Several physicians from around the world sought out the LRG to speak to and find ways to collaborate on future endeavors.

Pharmaceutical companies shared the latest on their GIST clinical trials and innovative trial designs to help advance the GIST field.

I encourage you to watch this video of global GIST medical experts sharing what they love about the LRG.

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We look forward to the potential collaborations and are grateful for the recognition for the work we do to ensure the survival and well-being of GIST patients.”

Denisse added, “It was such an honor to represent the Life Raft Group at such wonderful meeting. I had the opportunity to present our poster with the results from our Comprehensive Genomic Sequencing Study and to learn about the amazing research that is currently being conducted in sarcomas. We met with wonderful sarcoma leaders and stakeholders to discuss future collaborations to continue with our mission of accelerating GIST cancer research. Thank you, CTOS and all the organizers for a fantastic conference!”

Our colleague, David Josephy, President of GIST Sarcoma Life Raft Group Canada and a LRG Science Team member, enhanced the CTOS experience for us by summarizing relevant GIST research presentations and posters, and by sharing his amazing photography skills.

We asked GIST Specialists attending CTOS what they love about the Life Raft Group.



His summary of key research can be found here: [bit.ly/CTOS-Summaries](https://bit.ly/CTOS-Summaries)

The Life Raft Group's Poster at CTOS





# A Conversation with Dr. Jason Sicklick

Research is the key to finding a cure and effective treatments for a rare disease. There are many ways in which we move research forward. One of our major strategic goals is to increase contributions to scientific advancements such as publishing findings in peer-reviewed journals, aiding in the process of guidelines development and clinical trials development.

We also directly fund research. In this interview with researcher & surgical oncologist Dr. Jason Sicklick (Moores Cancer Center, UC San Diego Health) shares about his passion for SDH-deficient GIST research. At a recent GDOL, the LRG designated Moores Cancer Center as a Center of Excellence and presented Dr. Sicklick with a check towards his research.

Dr. Sicklick was a presenter at Life Fest 2022, and the LRG had the opportunity to ask him some questions about SDH-deficient GIST.



Deputy Executive Director Laura Occhiuzzi presented Dr. Sicklick with a check for \$25,000 at a recent GDOL.

## Q. What is known about SDH-deficient GIST?

A. It's been historically thought that these were only tumors of the pediatric population or teenagers or young adults. But what we're starting to recognize is that they're occurring not only in that population, but even in older people. And so, it certainly spans the spectrum. What's more difficult about these as well is that a lot of them are hereditary. And so, it's not just the one individual patient that's at risk, but because it's hereditary, the genetic mutations have been passed down from one of the parents to the child. Not only is that individual with GIST at risk, but their family members may be as well. It speaks to the importance of really having the entire family worked up if a diagnosis of SDH-deficient GIST is made.

The problem with SDH-deficient GIST, the progress to date, is that it started off with a lack of recognition that it was a distinct type of GIST. And then subsequently identified as a unique disease. And over the last 15 years or so, we're starting to understand more about some of the nuances and some of the different genes, whether it be SDHA, SDHB, SDHC, or SDHD, that are mutated in these, as well as most recently in the SDHC epimutant tumors that are not hereditary. These generally only occur in young girls, and we don't clearly understand why they're developing this.

But what's sort of hampered the field is a lack of ways to study this in the laboratory. And we can't find drugs that work because unfortunately, all the common drugs that we use for KIT mutant GIST, or PDGFRA mutant GIST generally don't work for these SDH-deficient GISTs. And so, the big task for us is trying to develop models to be able to study this. And we further have to think about the fact that, unlike some of the common GISTs that we see with KIT mutations that occur in a very specific area of the gene and that's more commonly seen mutated set of mutations - the SDH mutations can occur anywhere within one of these SDHA, B, C, or D genes and they may have different effects on the biology of cells. There's so much more heterogeneity within these tumors and that just adds another level of complexity.

## Q. In your research, are you looking at how SDH is activated as well as what drugs are affect it?

A. So, when you're looking at SDH, as research, if you could grow more cell lines, you have enough tissue, what are you looking to do, you're looking for, how it's activated, or only what drugs are affecting. We're looking for both really. We're now actively trying to recruit samples of tumor tissue from around the country, so that we can create a bank of cell lines that represent a broader span of the heterogeneity of these tumors. And so, we've been working with The Life Raft Group. Patient advocates are a critical factor in trying to identify where individual SDH patients are around the country and helping to recruit

them in order to procure tissue for making cell lines. Several years ago, we didn't have any cell lines, and with little bit of luck and a little bit of hard work, my laboratory was able to create the first sort of reproducible method for generating these SDH cell lines.

We've currently published our work on three of them. And we've got another five in the process in the lab right now that we're currently developing. But ideally, would be to have a huge repertoire of numerous tumors that represents the broader spectrum of this disease, so that we can then start figuring out what's different about an SDHA versus a B versus C versus a D versus an epimutant? What's the same? Even within a tumor, are they behaving differently? Are they responding to drugs differently? It opens up the possibility for not only for screening drugs and understanding how the drugs work relative to the biology of the cells, but also for trying to think about if we can maybe approach these in a more personalized fashion where we're figuring out the right drugs for that individual patient or for that group of SDH patients, rather than lumping them all together and assuming that every SDH-deficient tumor is exactly the same.



As part of our research focus for this week for in the Good News Holiday Campaign 2022, Dr. Jason Sicklick shares his passion for SDH-deficient GIST research in this video. See how your donation moves #GISTresearch forward.

<https://youtu.be/FVozRSvmHC8>

# A Conversation with Patient Advocate Sarah McGoram

My GISTory started about 26 years ago, when I was 18 years old. Actually, it probably goes back further than that, but I was diagnosed 26 years ago when I was 18. I'd been unwell for probably about four or five years prior. There were a few misdiagnoses, and I was in and out of hospital and eventually in 1996, I was diagnosed with GIST.

And being 1996, there wasn't really much known about the disease. I think it was one of the first in Canberra to be diagnosed. There were two tumors that had been removed in surgery. They had ruptured and caused problems. And this left 50 seedings of tumors in my small bowel when I was diagnosed. At the time, they sent me home and said, "There's no treatment, no cure and not a lot that we can offer, but we do know that there's no chemotherapy and radiation available. So, we won't try that, but there are no alternatives. If there's any problems in the future, then we'll just treat the

symptoms." I went home as an 18-year-old trying to work out what to do next.

At the same time, they said with the number of tumors my likely prognosis was about 12 months. That was a lot to handle and a really difficult diagnosis to come to terms with. That kind of reset the way that I was living life and viewing life. I had a sense of living on borrowed time and trying to make the most of every opportunity that I had.

About four years later, the tumors ruptured further, and I ended up back in hospital in the ICU losing about 50% of my blood volume in this one dramatic moment. And it was at that time that the very first



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Tom & Sarah McGoram

Glivec and since then I've had such a complicated history. I've gone through Glivec, about six different major surgeries, a Whipple procedure, had quite a bit of my digestive system and most of my small bowel removed plus my pancreas and spleen.

As I said I was on Glivec for a while but then had progression, and then moved on to Sutent. I am now on regorafenib, which I've been on for the last five years. Each of those have stopped the progression of my tumors until like with many people with GIST the treatments will work for a while and then you move on to the next. For whatever reason I'm on my 7th year of regorafenib and it has stopped the progression of my tumors.



Glivec trial had arrived in Australia. I was eligible for that, as were I think, about 20 other patients in Australia. That was the very first time I had a treatment option. It was 2001 when I commenced the Glivec trial. From that point on, I've been treated for a few years with

2015 was another significant year because I ended up with liver lesions. The GIST had spread to my liver. I had half of my liver removed. And then whilst recovering, the good part of my liver ended up developing a few lesions. So that's when I commenced regorafenib. Seven years now on regorafenib and it has stopped the progression. Long may that continue!

Also in that time, as part of my GIST journey, I had four years at uni, got my teaching degree and had a 20-year teaching career. We were lucky enough to have our son George in 2006 (that was with a pause in Glivec). Lots of life packed in there and married to Tom and yeah, so it's, been a busy, GIST journey, life journey. It's just intertwined with daily life as it is for so many other patients.

I guess what one thing I did forget to mention that when I was first diagnosed, all we knew was that it was GIST. I didn't know much more than that. But thanks to subsequent testing, and all the mutational analysis and biopsies from each of my surgeries, we've learnt more and more about it. And I know that I have the pediatric wildtype SDHB positive; that's the subgroup.

I'm learning more and more every year as I meet other people with different subgroups and lean on The Life Raft Group for all of their expertise as to what it all means and how it all fits. So that's my GIST journey in a nutshell.

Sarah is a passionate patient advocate for GIST patients in Australia. You can read more about Sarah's story here:

<https://liferaftgroup.org/2021/12/advocate-for-better-access/>

<https://liferaftgroup.org/2021/09/australian-gist-advocates-overcome-obstacles-qinlock/>

Watch for more from Sarah in the coming week!



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



[bit.ly/LRG-GoodNews](https://bit.ly/LRG-GoodNews)

# Thank you



Dina for Your Exceptional Service to the GIST Community!



When I attended my first LRG support meeting with others who had GIST (2003), I was recently diagnosed and very scared. I saw that I was not alone, and by hearing what they were going through and how they handled it, I gained a feeling of security. There are others! We can help each other! That gave me strength. I wanted to provide that same sense of community to others with GIST.

Once I became Support Group Leader for SoCal I held group meetings in different parts of Southern California (at that time, we had a NoCal leader, as well). In-person meetings had the benefit of seeing each other, spurring on camaraderie among us. I found a sense of worth when talking to newly diagnosed patients, spouses, and parents who just joined the LRG. This was all so new to them. They were beyond scared. By just listening to them speak, cry, ask questions, I could soothe their fears and provide suggestions. I knew that this was time well spent.

Eventually the NoCal leader retired, and I took over as State Leader for California. Due to the pandemic, we changed to Zoom meetings, which had the benefit of allowing people hundreds of miles away to participate. This was made possible by Laura Occhiuzzi, Diana Nieves, and Jessica Nowak, who ran these Saturday morning Zoom meetings from New Jersey.

In closing, I would like to thank the Life Raft Group for their support and care over the years. Each person with whom I worked has been professional, knowledgeable, and always helpful. The volunteer work that I have done has truly been rewarding.

I found a sense of purpose when I found the Life Raft Group. ”  
- Dina Wiley

GISTer **Dina Wiley** has been an integral member of our Life Raft Group family and embodies all the best qualities of a patient advocate. At the conclusion of 2022, Dina will step down from her post as SoCal representative.

Dina's insights and wisdom were gained from her own GIST experience, including a long period of misdiagnoses, and her determination to advocate for herself has enriched the lives of many GIST patients.

Once correctly diagnosed with GIST, Dina connected with Floyd Pothoven, LRG's former SoCal representative and she began attending his local support group meetings. Those meetings were significant, because as the members shared their experiences, she realized that she was no longer alone. She saw these meetings as a pivotal point in her fight against GIST. Dina's desire was and always has been to keep the flame burning by providing opportunities for others with GIST to be informed and share their stories while they offer and receive support.

She 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. Though she is stepping down from the leadership of the SoCal support group, Dina will always remain a valued member of our GIST family.





## The Perfect Gift

By Mary Garland

Senior Director, Communications

- + Regardless of your cultural background or traditions, the holidays are a time when people traditionally exchange gifts. There is pressure to become the perfect gift giver, taking into consideration the recipient's preferences and needs.

Outside of the commercial aspect of gift giving is a wonderful opportunity to share a different kind of gift, especially when considering loved ones who may be cancer patients and caregivers.

Here are some suggested gifts from the heart for patients and caregivers:

### Patients

- Give the gift of time. Share a cup of tea, watch a favorite movie or television show together.
- Offer to take them for a walk, or a drive to enjoy local scenery.
- Make your favorite recipe to share.
- Share one of your favorite books with them.
- Have a favorite picture or an inspirational quote framed
- Offer to accompany them to an appointment.
- Make a coupon book with invitations to do some fun things together.
- Show them that you see them. Bring a magazine related to one of their interests. Share some time doing something they care about. Let them know they are more than a patient.

### Caregivers

- Offer to help with taking their loved one to appointments.
- Bring them a homecooked meal that is easily frozen.
- Take them out for a brief excursion - a walk, a trip to a local coffee shop, a local holiday event.
- Make a coupon book with invitations of helpful things you can provide: a meal, helping with gardening, laundry, etc.
- Listen. It is the best gift you can provide.
- Call regularly. Let them know they can always share their frustrations with you.
- Let them know you see them. Show an interest in sharing subjects other than caregiving.

**Most importantly, let your loved ones know they are not alone.**



## Night to Fight Cancer Is Officially Back in New York City!

By Jessica Nowak

Director, Outreach & Engagement

After three long years, the 19th Annual Night to Fight Cancer benefitting The Life Raft Group's research programs hosted by Jerry Cudzil and Matthew Knopman took place IN PERSON on October 20th, 2022 at Midtown Loft and Terrace in New York City!

Jerry and Matt were beyond overwhelmed that after two years of Virtual NTFC events, over 150 participants came to continue to support this long-standing, fundraising event! Throughout the COVID Pandemic many things have changed, but the support for Jerry and Matt has remained strong.

Just as Night to Fight Cancer was back, so was our fantastic catering team - Scoози Events! Our attendees enjoyed the State Bird Modern Buffet Station accompanied by buttermilk biscuits, mac & cheese and a green goddess salad with their specialty cocktail of the evening "Cool as a Cuke." Guests finished the night with Scoози's famous Deconstructed S'mores, assorted cakes, and cocktail gummy bears.

While casino games took place on the terrace, the poker tournament took place on the main floor so all guests were able to see the lively game! **Congratulations the winners of the evening:**  
**1st Place: Jeff Leach, 2nd Place: Michael DiSanto, & 3rd Place: Michael Lee!**

A special thank you goes out to our corporate sponsors. First, our Club sponsors, who donated \$10,000: Bank of America, Capital Markets, Credit Suisse, Jefferies, Tradeweb, and Trumid and our Heart Sponsor which donated \$5,000: Morgan Stanley. Many thanks to our beverage sponsor Lyon Carter III for his continued support year after year and thank you to all of volunteers for the evening including Board Member Teena Petersohn, former LRG employee Kathrena Aljallad and volunteer Jasleen Kaur, and our award donors Keens Steakhouse and Sojo Spa.



*NTFC Hosts Jerry Cudzil & Matt Knopman*



*Left to right: LRG Executive Director Sara Rothschild, Michael Lee (3rd), Michael DiSanto (2nd), Jeff Leach (1st), and Co-host Matt Knopman*





## Water of Life Fall Event



By Dr. Matthew Lurin  
Water of Life Ambassador

On November 2nd, the Life Raft Group and I hosted the 5th Water of Life Fall Event, the WOLF. This annual "Once in a Lifetime" event is a gathering of several philanthropic whisky enthusiasts, as well as some of the greatest brands, whether their Ambassadors, Importers, Distillers, Retailers, Auctioneers or Owners. With the dinner portion held at Keen's Chophouse and Cigar Hours at the Carnegie Club, folks get the opportunity to experience wonderful flavors all in the name of charity.

This year we had several returning favorites as well as a few new attendees. Flying all the way from Scotland for his first WOLF Iain Allen brought us not one, but 2 Glen Moray Whiskies straight from 2 very different casks, after 34 years of aging. Sadly, another Iain, Iain McAlister was unable to make it, so he graciously shipped over a Glen Scotia still in the cask, from 1991. Robin Coupar and Raj Sabharwal also were unable to attend, but the 1958 distilled Glen Grant from Gordon & Macphail and the 1989 Linkwood from Blackadder were fantastic to enjoy.

We raised Raj's dram both to those we have lost since we started our first event, and those unable to attend this year. Speaking of Gordon & Macphail Richard Urquhart was in attendance and brought us an amazing 1979 Glentauchers as well as a 40 year old Benromach. Add in our opener, a rare waxed AH Hirsch from the 1980's from Joe Hyman, the 1988 Bunnahabhain from Sam Roe, the 25 year old Glenrothes from our newest Lifer Jennifer Blair, three wonderful and unique Benriachs from long time Lifers Gary Pickard and Greg King, a Keeper of the Quaich Talisker from



Pat McCarthy at Bayway, the newest Octomore 13.2, our annual closer for part one of the event from Jason Cousins of Bruichladdich, and a wonderful 21 year old Canadian Rye called "Good Day" (how apropos) from Dave Schmier and Batch Three of Flintrock from JJ Corry and Jena and you certainly have the makings of a ridiculous dinner. Several of these "Show Stopping" drams alone were worth the price of admission, but when you have the opportunity to try them all, and enjoy an amazing meal there really is no way to have a description do it justice. Then onto part two.

Cigars were a big hit, as we had our first ever branded cigars (see photos, thanks Yoni), and the opportunity to pair them with several amazing drams. John Glaser, who's company Compass Box has been a supporter since year one donated his wonderful Three Year Old Deluxe whisky (IYKYK), Forbes Malcom from the Loch Lomand Group gave us a delicious Loch Lomand aged in Kerr wine casks, and among the other mouth watering gems there was a 17 year Tobermory, an 18 year old Glenrothes, and Matt Hoffman himself and long time lifer Devin Volardi of Westland came by with some unreleased samples because "why not?"

Pat had an old Bayway selection of a single cask Bruichladdich finished in a rum cask as well, though apparently his Uber consumed about a third, lol.

*Continued on next page*

Even our guests pulled out some bottles to try and the Ardbeg Smoketrails made an appearance as well. Thanks James.

On top of all of this, Ewan Morgan from Diageo made an outstanding donation of a set of sought after samples, including the Talisker 30 year old.

The winning bid was \$675, truly making someone quite happy!



All in all this was one of our greatest and most memorable events. Raising close to \$12,000 for The Life Raft Group certainly was icing on this many layered cake. The food, the pours, the sticks and the company were all incredible and we look forward to doing this again next fall. Perhaps you can join us next year when we raise our glasses and Drink Whisky to Fight Cancer, but be quick, tickets do sell out quickly. Can't imagine why 😊

## Thank you to our Major Donors: August to November!

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An email community for GISTers  
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## Thank you to our members!

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Our prayers go out to the families of two GEMs donors, Jeffrey Jobe and Colleen Carney who passed away this year.



## Thank you to our 2022 event sponsors!



### GDOLs



### Life Fest

### Night to Fight Cancer



## Calendar 2023 - Visit: [bit.ly/LGREvents2023](https://bit.ly/LGREvents2023)

**La Senda Verde Virtual Tour**  
**Jan 18, 2023 10am ET**

**GIST Updates from CTOS**  
February 8th, 2023 • 7pm ET



Dr. Herbert Loong  
The Chinese University of Hong Kong

GDOL Northern California - Spring 2023 - Details TBA

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