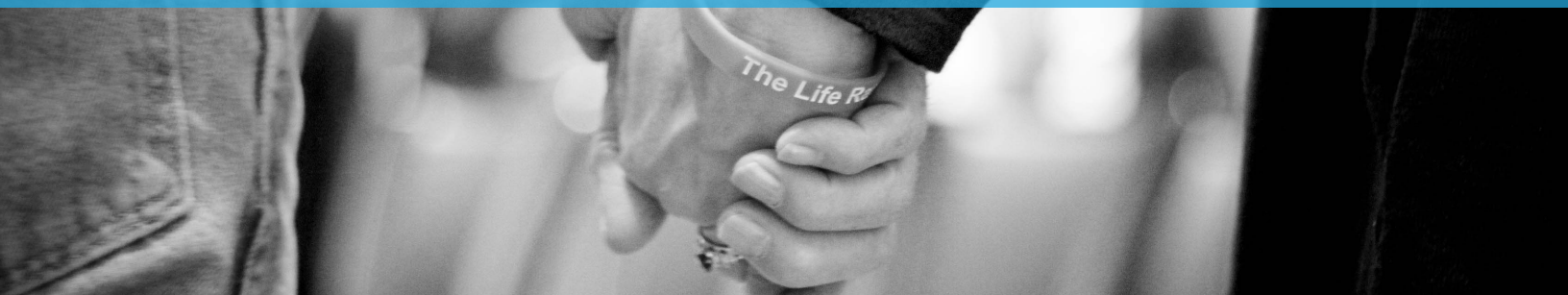


Ensuring no one has to face GIST alone



In Loving Memory: Royce Williams, Lenny Cervenik, Jo Anna Turner

Sisters of the Heart for a Cure

By **Jessica Nowak**, LRG Director, Outreach & Engagement



Michele MacLea & Wendy Williams

Wendy Williams became a member of The Life Raft Group in August of 2017. She was introduced to the LRG by one of her closest friends, Michelle MacLea, whose son Connor was diagnosed with SDH-deficient GIST in 2017.

Wendy and Michelle met in a Lamaze class when they were pregnant with their first children. From there, a lifelong friendship began. Their eldest children were born a day apart and their second-born children three months apart, so their families are very close.

Wendy joined our community so she could learn more about GIST for herself. Through reading materials from our website, newsletter, and the ListServ email community, both Wendy and Michelle gained knowledge about GIST while establishing a strong sense of community with the LRG.

In a recent interview, Wendy shared that in the beginning one of the obstacles Michelle faced was finding the best care for Connor. There is not always an open line of communication between doctors and GIST Specialists. What stood out to her was the amount of coordination and data collection that the LRG provides utilizing tools such as the LRG Patient Registry and GIST Collaborative Tissue Bank.

► see **WENDY** on page 4

Are YOU Seeing a GIST Specialist?

LRG Patient Registry Shares Survey Results

By **Jennily Eshak**, LRG Patient Registry Associate

When being diagnosed with any type of disease, it is important to see a specialist. A specialist will have the proper experience to guide you in the right direction with your treatment. Due to the rarity of GIST, healthcare providers play an important role in the journey of a GIST patient. The Life Raft Group Patient Registry wants to assure that every GIST patient has access to the best care possible

The purpose of this LRG survey was to study the correlation between treating oncologists and patients' satisfaction in terms of treatment and guidance.

► see **SPECIALIST** on page 3

Increasing Survival Without Borders

New 'GIST Regional Registry Latin America'

By **Denisse Montoya**, LRG Patient Registry Director

Patient registries are organized data platforms that use observational research methods to gather data for scientific, clinical or policy purposes.

The Life Raft Group is pleased to announce the official establishment of our Regional Patient Registry, a partnership with Latin America, which will collect medical history and treatment information from more than 600 GIST patients who are represented by Fundación GIST Mexico, Fundación GIST Chile, and Pontificia Universidad Católica de Chile.

► see **REGISTRY** on page 4



I went to bed last night and had a crazy dream. *What if?*

- ... We could create a community of patient advocates, medical professionals, pharmaceutical companies, government and more.
- ... We would be operating out of a base in Wayne, New Jersey, with offices in Virginia and Chile, with representatives in 57 countries.
- ... We could create consortia with the most prestigious researchers in the world and discuss the need to provide help for diverse populations over lunch with the former Vice President of the United States.
- ... We could provide hope and support to patients and caregivers who are simply struggling to survive.
- ... And support it all with the largest and most sophisticated patient-driven GIST database in the world.
- ... And do it all to fulfill the saying in the Jewish Talmud that *"He who saves one life saves the entire world."*

Imagine doing that, again and again, life after life after life.

*When I wake up,
I realize I wasn't dreaming.*

The dream is alive *because of your help.*
Travel with us in 2020
on the path to survival.

Norman J Scherzer

► SPECIALIST continued from cover

We reached out to LRG members

(both Patient Registry members and non-Patient Registry members) via email, phone, the LRG Facebook Page and ListServ. Analyzing the data aided the Patient Registry in formulating an action plan of how to better help patients.

We received 378 responses from 26 countries. 83% of responses were from the U.S. and 17% international.

The first question was "Are you seeing a GIST Specialist?" This question split our subjects into two cohorts (groups). Utilizing our LRG GIST Specialist list, we were able to verify if each of those patients was actually seeing an oncologist who is a GIST expert (Figure 1).

Note: Some patients did not respond to all the questions on the survey so numbers will not always add up to group totals.

Figure 1. Are you seeing a GIST Specialist?

Group 1	Group 2
YES (263 responses) 164 seeing actual GIST Specialist 86 not seeing a GIST Specialist 13 did not respond	NO (115 responses) 7 seeing actual GIST Specialist 105 not seeing a GIST Specialist 3 did not respond

We asked patients if they would recommend their GIST specialist to other patients battling GIST (Figure 2).

Figure 2. Would you recommend your GIST Specialist?

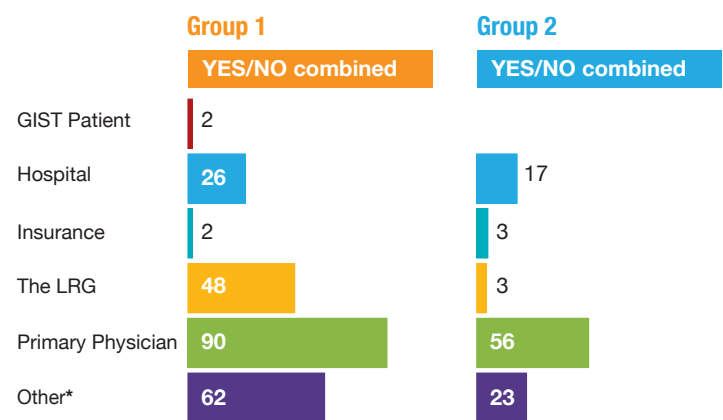
Group 1	Group 2
YES 226* would recommend doctor 154 of those doctors are actual GIST Specialists 79 are not GIST Specialists *Number is skewed because some patients reported multiple doctors and some patients did not respond	NO 2 would NOT recommend 1 is an actual GIST Specialist 1 is NOT a GIST Specialist

Group 2	
YES	NO
82 would recommend doctor 6 of those doctors are actual GIST Specialists 76 are not GIST Specialists	12 would NOT recommend NONE of those doctors are actual GIST Specialists

Based on these totals we asked each group who referred them. Knowing who referred our patients to their specialist is critical. It is important for a GIST patient to be treated properly and to see a doctor that understands the complexity of GIST.

The patients in our survey were referred by other patients, their doctor, their health insurance company, a hospital, The LRG or through their own research, friends or family (Figure 3).

Figure 3. Who referred you to your GIST Specialist?



*Other includes research, friend, family member, internet, other organization, do not recall

Next, we asked, "Does your specialist answer your GIST-related questions?" (Figure 4)

Figure 4. Does your specialist answer your GIST-related questions?

Group 1	Group 2
YES 225 said doctor answers GIST-related questions • 221 of these patients recommended their doctor, 1 did not, 3 did not answer	YES 76 said doctor answers GIST-related questions • 71 of these patients recommended their doctor, 4 did not, 1 did not answer
NO 6 said doctor answers GIST-related questions • 5 of these patients recommended their doctor, 1 did not	NO 26 said doctor answers GIST-related questions • 8 of these patients recommended their doctor, 8 did not, 10 did not answer

What we took away from this survey

By doing this analysis, we were able to see that there is an increased instance of seeing a GIST specialist when a patient is a part of the Patient Registry. Of the 378 respondents, 219 are in our Patient Registry. 160 of these Patient Registry members responded yes to seeing a GIST specialist, while 59 responded no.

The survey set out to determine whether there was a correlation between treating oncologists and patient satisfaction measured by willingness to recommend and refer their doctor. Patients who saw a GIST specialist were more likely to do so and receive proper treatment.

Next Steps

The results of this survey have initiated a project to identify new GIST specialists in order to expand our database, further analyze the impact between seeing a GIST specialist and the overall survival among LRG Patient Registry members and continue to advocate for patients to see a GIST specialist.

Need a GIST Specialist? liferaftgroup.org/gist-specialists

► WENDY continued from cover

Wendy said, *"With SDH-deficient GIST*, there is more of an unknown because the lines of treatment are even more obscure. The wealth of information the LRG provides is unmatched. The staff is warm and welcoming and really wanted to help me learn. The work the LRG does helps others feel a great sense of community which allows others suffering from GIST know that they are not alone."*

Michelle and her family began their campaign to spread awareness about GIST by passing out LRG bracelets and pamphlets to her community. Wendy knew she wanted to do more. Through her real estate business, she began donating ten percent of her sales commissions, which was the beginning of her fundraising campaign *Bring Home a Cure for Connor*. Through this effort, Wendy is helping to raise funds for #GISTresearch and also spreading awareness about GIST to people who have never heard of this rare cancer.

"I knew that donating these funds for research would help other families who have the same struggles," said Wendy.

When Wendy first began *Bring Home a Cure for Connor*, she explained it was not an overnight process. It began with creating a name and a logo. She worked with members of the LRG

regarding the idea and GIST materials, and with marketing consultants to brainstorm different ideas. With these resources, she was able to come up with a concept that has a connection to what she does for a living.

"When people join together and move forward with a sense of innocence, a sincere willingness for what could or might happen, things blossom, and in a true form that's where miracles come from. There is not always a textbook answer, but when you combine genuine people with a fundamental mutual goal the universe can align."

- Wendy Williams

Once the basics were in place she met with Michelle for her consent. Wendy remembers a heartfelt moment telling Michelle, *"If nothing else, my goal is to give you a sense of support. At the end of the day, if you feel that...then I have succeeded."*

Wendy commented on the process of beginning a fundraising effort:

"When people join together and move forward with a sense of innocence, a sincere willingness for what could or might happen, things blossom, and in a true form that's where miracles come from. There is not always a textbook answer, but when you combine genuine people with a fundamental mutual goal the universe can align."



She cites the formation of the Pediatric & SDH-Deficient GIST Consortium that was spearheaded by the Life Raft Group as an "unbelievably important" research effort, stating, *"Who else is doing something like this?"*

Wendy believes that the more support you can have when you're facing a GIST diagnosis makes a difference.

"Maybe at first it is hard to reach out if you are a more private person, but you never know what information others provide that might be meaningful or be exactly what you need to hear. Being a part of the LRG community will help provide you with information and connect you to others facing GIST so you will never be alone."

The Life Raft Group is grateful for the continued support and generosity Wendy has shown our LRG GIST Community!

*SDH-deficient GIST differs from KIT/PDGFRα positive GIST in that it tests negative for KIT/PDGFRα and stains negative for SDHB. SDH-deficient GIST is typically found in children and young adults. For more info on SDH, please see our FAQ sheet at: <https://bit.ly/SDH-FAQs>

► REGISTRY continued from cover

Salud con Datos (Health with Data) was formed in 2016. This initiative's main goal is to strengthen its efforts in Latin America as it focuses on harnessing data to improve GIST patient outcomes.

Through this partnership, representatives from Latin American countries will be able to enter GIST clinical data from patients into the LRG's Patient Registry. This de-identified information will then

be used for research to improve diagnoses, treatments, and quality of life for patients. Latin America needs collaborative initiatives like this to represent patient voices to regulators.

The LRG will analyze the deidentified data to identify gaps in care and to compile relevant information to improve knowledge and awareness about GIST, ultimately sharing their findings with patients, advocacy groups, health care professionals, and researchers.

Rodrigo Salas, President of Fundación GIST México and member of the LRG Board of Directors states:



"Participating in a regional patient registry through Salud con Datos is an excellent opportunity that has allowed us to develop cross collaborations with the medical community in order to advocate

▶ REGISTRY continued from page 4

with our local authorities for better diagnoses and treatment for our patients."

Many patients in Mexico lack access to GIST treatment and one of the goals of this Regional Registry is to collect relevant data to demonstrate to policy makers the correlation among therapeutic access and overall survival.

Rodrigo commented, *"With real world evidence, we obtain reliable information regarding costs of treatments for GIST patients. This will influence authorities to include GIST in the public health coverage. We also have showed our government the importance of an epidemiology surveillance system and have promoted the development of a local cancer registry in Monterrey, México."*

Finally, we understand the only way to move GIST research forward is to work collectively.

Rodrigo said, *"Research and advocacy together are great tools to have better outcomes for our patients."*



*Piga
Fernández*

Piga Fernández, Executive. Director of Fundación GIST Chile and Global Consultant at The Life Raft Group as well as a GIST patient, shared:

"Salud con Datos has been a great project for Fundación GIST Chile and a great opportunity. On one hand, the data has given us the tools we needed to advocate for GIST patients' needs, and on the other hand it has given us the opportunity

to show nationally and internationally the work we have done collaborating with the LRG, Fundación GIST México, as well as working together with clinicians, academia, and scientific societies in Chile."

Mutational testing is key for treatment optimization for GIST patients. As in the U.S., Latin American patients do not usually get mutational testing prior to starting treatment. Data from the LRG Patient Registry has shown that patients who know their mutational status have a higher overall survival than patients that do not.

Piga adds, *"From the advocate's perspective, this Regional Registry will provide us with the Real World Data we need to make the needs of GIST patients visible, such as the importance of a timely diagnosis and effective treatment patterns. It will give us enough information to advocate for access to treatments and diagnostic tests such as mutational tests."*

Our aim is not only to educate decision makers on the needs of GIST, but also patients. We want to encourage all patients from all over the world to feel empowered with regards to their GIST.

Piga said, *"The clinical de-identified data from this Regional Registry will give us enough information to disseminate knowledge to create awareness of the disease."*

The Support Team in Oncology Research and Medicine (STORM) within Pontificia Universidad Católica de Chile (PUC), is a key player and partner in this collaboration.

Oncologist Marcelo Garrido specializes in GIST and Neuroendocrine cancer and is an Assistant Professor at PUC School of Medicine. Matías Muñoz is the data entry and data analyst of STORM, with many years of experience in data analysis and nuclear medical technology.



*Analyst Matías Muñoz and
Dr. Marcelo Garrido*

Garrido and Muñoz shared: *"Since 2016, our oncology research team has been working cooperatively with Fundación GIST Chile to actively refer patients to specialists, advocating for patients during their diagnoses and therapies; as well as providing them with information, tools, and resources to make better decisions and face their disease the best they can. It's been an amazing opportunity to work with highly specialized professionals and patient advocacy groups through academic collaborations to research this field and modernize GIST patient care, all while benefiting patients which is our shared goal within this partnership."*

GIST is so rare that collaboration is crucial to understand the clinical patterns and traits of the disease among all GIST patients. Real World Data (RWD) will help us observe this in a broader spectrum.

Dr. Marcelo Garrido and Matías Muñoz said: *"Working together as a part of Salud con Datos by contributing real world data for a regional patient registry is exciting, expanding the possibilities of researchers and patients as well as progressing step by step to what we all desire: overcoming GIST once and for all."*

RWD from this partnership will help to create a patient profiling study, where many important factors can be identified and compared among countries. The objective of this international collaboration is to study and analyze the epidemiological factors of GIST

▶ REGISTRY continued on page 6

among patients across the world. We envision that the outcome of this international collaboration will change health policies, assist with patient advocacy, and increase patient survival. We look forward to the outcomes this partnership will bring to the GIST community and the enormous impact on all GIST patients, despite the location of residence of patients.

Moving forward, we aim to expand participation and consolidate more GIST knowledge by inviting other countries and stakeholders to join us to improve overall patient survival and access to treatment in Latin America and globally.

Fundación GIST Mexico - A nonprofit founded by Rodrigo Salas for GIST patients. Fundación GIST México was born in memory of his wife, Cordelia Gutiérrez de Salas, who was diagnosed with GIST in 2000. Our mission is to



promote the survival of GIST patients. Learn more: <http://fundaciongist.org/>



Fundación GIST Chile - A nonprofit founded in 2015 by GIST patient Piga Fernández. Their mission is to improve the quality of life and survival of people with gastrointestinal cancers, respecting their dignity and autonomy, in the phases of prevention, diagnosis and treatment, through accompaniment, education, information, support to research and advocacy. Learn more: <https://gist.cl/>

Pontificia Universidad Católica de Chile, STORM - The mission of the Support Team in Oncology Research and Medicine is to generate, manage, improve and facilitate the development of basic and clinical research of excellence in the area of medical oncology. Learn more: <https://www.uc.cl/>



How Technology Is Changing the Way We Look at Health Data & How Patients Are Critical to Its Success

By **Pete Knox**, Senior Director, Research

I was honored to represent The Life Raft Group and GIST patients at ISPOR's 2019 European Conference, held November 2nd-6th in Copenhagen, Denmark. In addition to the standard meetings and poster sessions, I was asked to participate in two speaking sessions - the plenary session that opened the conference, and a smaller more focused session that gave details about the activities of ISPOR's Real World Evidence (RWE) special interest group, which I and the Life Raft Group are especially proud to be a member of. ISPOR is a global organization that focus on Health Economics Outcomes and Research (HEOR) and how it can be used to improve patient outcomes. Membership comes from the pharmaceutical industry, the research community, vendors that provide data tools and economic models, and also patient advocates.

As valuing the patient perspective is quite in line with the LRG's mission, I did not hesitate to accept when asked to speak at the conference. The plenary session was attended

by between three and four thousand people and was also recorded for archiving on ISPOR's website in the near future. I participated in a panel that also included representatives from the Copenhagen Institute for Futures Studies, Microsoft, Phillips Healthcare, a patient advocacy foundation from Madrid, Spain called Foundation 29, Erasmus University, Netherlands, and Flatiron Health. Throughout the panel I was able to articulate the importance of combining real world evidence (RWE) with data from clinical trials and electronic medical records (EMRs). The Life Raft Group has been involved in the collection and analysis of RWE for many years, and both my fellow panelists and the audience members I spoke to afterwards seemed rather impressed with our approach to data.

I was also able to advocate for including the patient perspective in the data collection process: asking questions that are of importance to

patients, recognizing that patients are not only providers of data but also educated consumers that want to understand what their data can tell them about potential treatments and quality of life, and see that their data makes a difference in the lives of other patients, and also finding ways to value their data in ways that motivates them to continue contributing it.

In addition to the plenary session, I was able to speak with various researchers about the RWE special interest group, all of whom agreed that RWE and inclusion of the patient



From left to right: Moderator Bogi Eliassen, Copenhagen Institute for Futures Studies. Panel: Julian Isla, Microsoft and Foundation 29; Alexandra Goncalves, Philips Healthcare; Elene Bonfiglioli, Microsoft; Pete Knox; Ernst Kuipers, Erasmus MC University Medical Center; Rebecca Mksad, Flatiron Health

NORD Hosts Summit

By Carolyn Tordella, LRG Assistant
Director of Communications



The National Organization for Rare Disorders (NORD) held a Rare Disease Summit in Washington,

D.C. this October hosting several thousand people comprised of patients, advocates, non-profit employees, health providers, IT developers, pharmaceutical staff, physicians and researchers, and representatives from government entities.

The event, entitled "The Rare Disease & Orphan Products Breakthrough Summit" was anchored on the theme "The Time is Now" with several dozen speakers covering a diverse range of topics which ultimately focused on one thing - results - concerning accelerating research, healthcare legislation, building patient registries, compiling natural histories, and insurance concerns for patients of rare diseases.

New attendees enjoyed a pre-Summit meeting featuring updates on the NORD Board's impact in 2019 and its plans for 2020. Vanessa Boulanger, Director of Research for NORD, shared on the newly launched collaborative projects with the FDA and the Critical Path Institute to standardize patient registries and accelerate rare disease characterization. After these presentations, a networking dinner provided diners an opportunity to discuss topics such as Advancing Research & Innovation, Patient Assistance Programs, Working with NORD for Disease Education, and Managing Patient Registries.

The Summit's keynote speakers included Terry Jo Bichell, Director of the Angelman Biomarkers and Outcome Measures Alliance, and Karen Aich of Lysogene, who shared their respective stories of their children's diagnoses, and how they devoted their lives as full-time researchers and biotech developers to find a cure and Alex Azar, U.S. Secretary, Health and Human Services who spoke about the President's healthcare concerns.

Breakout sessions included: Rare Disease Advisory Councils: A

Unified Voice Driving Progress, The Ethics, Impact and Ownership of Patient Registries and Natural History Studies, Overcoming Challenges for Patients and Manufacturers in Gene Therapy, Social Determinants of Health in Rare Diseases, and Fostering Dialogue and Developing Partnerships Among Payers, Providers, and Patients.

For the LRG, the takeaway is confirmation of the importance of the patients perspective, the power of patient advocacy and empowerment through information, and the impact of patient registry data on research. The diseases may vary greatly but the challenges and roadblocks posed by all rare diseases are similar. Noting how far we've come is encouraging, and realizing how far we've still to go can feel intimidating, but it is hopeful that organizations like NORD and major players like the FDA and other stakeholders are advocating and collectively making our voices heard so that we can work toward characterizing our rare diseases, hearing patients stories and natural histories, and using real word evidence to expand treatment options and work towards a cure.

"Patients and caregivers are our highest priority, much of the data that go into outcomes research and health economic analyses start at the patient level. Obtaining feedback, buy-in, and participation by patients or their representatives is imperative to the evidence-based process of defining and determining value at the core of health economics and outcomes research (HEOR). The Society seeks to create an environment where patients' expertise and knowledge are valued and incorporated for better research and ultimately better health outcomes. To achieve this goal, ISPOR includes patients in scientific discussions within the Society and facilitates the development of the "science of patient engagement" in healthcare research and decision making. ISPOR is the first research-focused organization to establish formal patient engagement groups in all major geographic regions."

- Lucinda Orsini, ISPOR's Associate Chief Science Officer

perspective are of paramount importance.

What I found especially interesting was that so many people came up to me after my speaking sessions (both immediately afterwards and over the next few days) to tell me that it was good to hear the patient perspective, and that prior to my comments they

hadn't really stopped to think of how important it was. While I found it personally gratifying that I had made an impact, it also showed me that we still have work to do if we are to deliver the message that the patient voice needs to be heard. We will continue to do that going forward, as it drives everything we do. Thank you

to ISPOR for allowing me to deliver that message and thank you to all of our patients for continuing to provide not only their data, but also for being the reason why we continue fighting to be heard.

For more information on ISPOR visit:
<https://www.ispor.org/>

Making the Most of the Holiday Season

By **Angela Edson**, Outreach & Engagement Associate

The holiday season is quickly approaching and the stress of the holidays can bring up mixed feelings for many people. When you are struggling with a cancer diagnosis such as GIST, the holidays can be an extra challenging time of year. For newly diagnosed GISTers and their families, this may be their first year celebrating the holidays. Long-term survivors and their caregivers may have created a routine that works best for them during this season. Of course, there are patients and caregivers who fall somewhere in the middle and are still learning to adjust to their diagnosis during this time.

We all have expectations of what our holidays should look like and often feel a sense of failure when they do not pan out the way we envisioned. It is always okay to express your concerns and needs during the holiday season as well as set boundaries with others.

It is important to keep in mind that while people may be supportive, not everyone is good at providing the same type of support.

One of the ways to remember the different types of support a person can offer is with the acronym FDR - Feelings, Doers, and Respite. Some of the people in your 'support circle' may be good at dealing with feelings and emotions. They may be able to provide you a listening ear or a shoulder on which to cry. Those who are doers may not deal with emotions well and are best at helping you out with daily activities and chores that need to get done. And lastly, respite. These are the people in your life who are good at distracting you during a difficult time and can help take your mind off things. Identifying these different kinds of people in your life can be helpful in managing your own expectations.

Here are some thoughts and comments from GISTers and caregivers about their concerns and challenges during the holiday season and how they have learned to navigate the holidays:

I was glad the holidays were over as I felt sad that this might be the very last Thanksgiving and Christmas that I experience. It has been a year now since my diagnosis- and a difficult one at that including recovering from major surgery recently- but my numerous tumors are currently stable, and I am feeling physically back to my normal self. It has taken me this full year to finally be at peace with my cancer. I am so looking forward to the holidays this year - celebrating being alive and with family. My priorities in life have changed a lot and I am motivated to take advantage of my feeling good right now and get involved with doing volunteer work- not just during the holidays but throughout the year.

Bettina – GISTer since 2018

Enjoy the holidays because things always come out better after they get really bad... But once I found the worst then it could only get better. Be close with family during holidays. Family is good to me. You are much more comfortable about dying when your family loves you and they are always there for you and then you feel more comfortable. Celebrate every day with a glass of champagne.

Manuela – GISTer since 2015

Heading into the holiday season has been on my mind. I intend on doing all the things that I constantly postpone until next Christmas - I love toy trains, and I have a fairly good size collection. Most of these trains run outdoors and are rather large. I haven't set them up for probably the last ten Christmas'...Well guess what? I intend on setting up at least one or two sets in my home!... I know that probably sound ridiculous to most people, but when you think you might actually die - it does change you in a very profound way, at least to me it did. I have no idea how long I will live, but I'm hoping I'll be around to at least see some grandkids.

John Paul – GISTer since 2019

I've learned to ask questions of our GIST oncologist, and advocate for my husband when needed. I'm not afraid to ask for help, and know it's okay to feel bad, sad and maybe even angry once in a while. I wish no one had this disease, but at the same time, so much of my life has changed for the better while helping my husband. Part of that change is to pass on what I've learned as a caregiver. I wish all a Happy Thanksgiving Day and wonderful holiday season. There is a life after GIST!

Marlene – Caregiver since 2010

We had long talks at night about taking care of myself and she [sister] was very kind. This started my journey to accept that I have cancer but not allow cancer to have me. I began to be appreciative for everything big and small and found a myriad of things to be happy about. This holiday I am looking forward to having a blast. I have loaded up the wine rack, made plans to visit family members and have already started Christmas shopping. I am thinking of having a big party for Christmas at my house. I had one prior to getting sick and it really turned out well.

Rob – GISTer since 2016

This is my 16th year of living with cancer. It has become so ingrained in the lives of my family that it is barely ever mentioned. I do not act sick, look sick, or really talk about it unless asked. I realize I'm not the typical cancer patient though. I don't see my cancer as a curse anymore, in fact I see it as a blessing. Cancer is the vehicle to which I was motivated to chase virtue and improve myself and my life. So, when anyone wants to talk about cancer, I'm happy to do so because I didn't always feel that way. To give meaning to suffering is the greatest gift I have to give, and it seems that is one of the vocations I have in life.

Jason – GISTer since 2003

Frankly, I have no memory of the holidays that year. I believe all I did was cry. Maybe not all the time, but a lot. I decided to give myself a year to process having a cancer diagnosis, and if crying and being afraid were part of it, so be it... It took some time to learn to live a different life than I imagined. I had a great amount of guilt that my husband had a sick wife to take care of. Over time, and with the support of LRG, I began to educate myself. With knowledge came a sense of power in the direction of my future. I changed oncologists a few times until I found the best one for me. I'm no longer living in fear. It may not sound like it from reading my story, but I am a very strong person. My cancer diagnosis humbled me. I've always been the friend to others with problems or health issues. Now I sometimes need help, and it's ok to ask for it... This year, my family will join us for thanksgiving. We never take each other for granted and spend much of our time together laughing. Maybe it's age, maybe it's cancer, or both. Life is sweeter, family is closer, friends are dearer.

Kay – GISTer since 2012

Hugs are powerful medicine. In order to spread the love around, Norman has decided to create a "Hugs Department." Co-directing this project are Anita Getler and Kim Tallau. Look for a new social media campaign in 2020. Sending holiday hugs to all!

**Thank You to
Our Major Donors
(October
& November)**

Carlos Baldor
BST Consultants
Jerry Cudzil
Dublin's Pub
Sandra Glassman
John Kirk

**Travel with us on the
Path to Survival**

**Make your holiday donation
today to #GISTresearch!**

<https://lifteraftgroup.org/donate/>



Night to Fight Cancer

Lights Up the Night for #GISTresearch

By Jessica Nowak, LRG Director Outreach & Engagement

The 16th annual Night to Fight Cancer (NTFC) took place on October 24th, 2019 at the Midtown Loft and Terrace in New York City. This annual event benefits The Life Raft Group's research programs.

LRG Board President Jerry Cudzil co-hosted the event with Matthew Knopman. Friends for over 16 years, Matt considers Jerry both a friend and mentor which is why he continues to support The Life Raft Group with his participation in this event and his generosity.

Jerry and Matt were overwhelmed by the immense amount of support and generosity from friends and family who attended the event. "Each year we are blown away by the number of participants, and this year's number did not disappoint!" said Jerry.

With close to 200 participants, we were able to raise close to \$200,000 for the Life Raft Group. With the funds raised from NTFC, the LRG will continue to enhance survival and quality of life for people living with GIST through patient powered research.



Back this year with catering was Scoози Events. Attendees enjoyed the Taqueria Streatery's pulled pork carnitas and carrot asada. The night's specialty cocktail was Rosemary Lemonade. Hors d'oeuvres included past crowd favorites Mini Big Mac and the Ramen Noodle Burger among others. Our guests ended the night with the famous deconstructed s'mores and crème brûlée.

While the poker event took place on the main floor, guests enjoyed casino games on the Terrace as the spire of the Empire State glowed nearby. By the end of a very exciting game the winners of the night were, Robert Scherzer, 1st place, Arie Bedell, 2nd place, and Eugene Gokhvat, 3rd place!



NTFC co-hosts Jerry Cudzil and Matthew Knopman

And let's not forget to thank all those who helped make this event possible! We would like to thank our NTFC

Ambassadors Brian Behrens, Lyon Carter III, Benji Cheung, Armando Petrucci and Netty Tsai for their continued support year after year. A special thank you also goes out to our corporate sponsors. Club Sponsors who donated \$10,000 included Bank of America, Morgan Stanley, Pfizer, RBC, and Tradeweb. Hearts Sponsors who donated \$5,000 included Cantor Fitzgerald, J.P.Morgan, and IMC. Many thanks to major donors Jerry Cudzil, Matt Knopman, and the Dan and

Stacie Allen Charitable Fund for their very generous contributions. In addition, we would like to thank Lyon Carter III who was our beverage sponsor, our volunteers Anthony Cashin and Cora Ramadan, and our awards donor, Murray Rosenthal.

Events like these support the research efforts of the LRG. If you would like to see how The Life Raft Group uses research monies, please visit our digital



library to view our donation and research fact sheet: <https://lifteraftgroup.org/library/>. More photos of the event: <https://lifteraftgroup.org/photo-galleries/>



First LRG GIST Mentor Training Takes Place in Wayne, NJ

By Diana Nieves, LRG Senior Director Outreach & Engagement

The Life Raft Group held a training for GIST Mentors (formerly known as the GIST Peers) from October 31st - November 1st, 2019 at LRG headquarters. An LRG GIST Mentor helps patients and their caregivers through their GIST journey - from receiving a diagnosis to navigating different resources of information, support, treatment options, side effects, etc. A GIST Mentor is a GIST survivor or caregiver who can offer you understanding and empathy.

Seven mentors attended the training: Santy DiSabatino (Director, GIST Mentor Program), Carolyn Dewalt, Julie Durkee, Eric Lindberg, Marlene Nei, Kay Stolzer, and Rob Taylor. The group met with LRG staff over a Halloween lunch and some games. After lunch, the first order of business was to change the name of the program from GIST Peer to GIST Mentor. The group, comprised of patients & caregivers, felt that mentor was a better name for what we are trying to accomplish with assisting fellow GISTers. By definition a mentor is an experienced and trusted advisor, therefore being called a GIST Mentor felt more meaningful to the group.

A GIST Mentor is a person who has knowledge from their own experiences with GIST either by having it or being affected by it through a loved one, and has received training to be empathetic and understanding in order to help those dealing with GIST. At the end of day one, the group received an in-depth explanation of the Life Raft Group's mission and history, GIST Prime, the LRG Patient Registry and listened to a GIST Expert Training led by David Josephy, of the Life Raft Group Canada.

On day two, the mentors received training on Self-Care for the Support Team which was led by Health and Life Coach, Sheetal Muhlon, Communication Training from Santy DiSabatino, and a session on Dealing with Anxiety & Uncertainty When Faced with a Cancer Diagnosis: How Do I Help the Patient/Caregiver presented by social worker, Hannah Marcus. The group created a mission statement, discussed the key points to a successful mentor support program and relationship with mentee, and developed an outline for a training manual for new mentors. They also suggested additional requirements for becoming a GIST Mentor.

The Training ended on Saturday with a certificate ceremony followed by a NJ Support Group meeting where the mentors shared their GIST journey stories to

local NJ patients and caregivers. The GIST Mentors will continue meeting virtually to further refine the program and to receive additional support to further assist those on their own GIST journeys. Stay tuned as this group of amazing volunteers spread their wings to help so many in our LRG community.

"Cancer is a lonely disease, and GIST even more so. I felt so isolated and alone the first year, even with my husband, who has steadfastly been by my side, my wonderful sons, and dear friends. I couldn't find anyone like me. Life Raft first gave me tools to learn about my cancer, empowered me to seek out a specialist, and share my story with people who "knew." You have created a massive tikkun olam in the GIST community. GDOLS, Life Fest, and our new Mentor program are not only educational tools, they allow us to connect, become part of a community; to move past our own struggles and reach out to others. The Mentor training will enable us to be better equipped to assist others in their journeys. Giving back helps us heal ourselves. Our amazing group became instantly close and lifelong friends. Thank you for the difference you and your staff have made in my life. You have all become family."*

- GIST Mentor Kay Stolzer



Left to right: Mentor: Julie Durkee, LRG Senior VP Laura Occhiuzzi, Mentors: Rob Taylor, Carolyn Dewalt, Eric Lindberg, Marlene Nei, and Kay Stolzer, LRG Outreach & Engagement Team Members: Diana Nieves, Angela Edson, Front: National GIST Mentor Program Director Santy DiSabatino

**tikkun olam* - A Hebrew phrase which is modernly and broadly understood as the notion of "repairing the world" through human actions. Humanity's responsibility to change, improve, and fix its earthly surroundings is powerful. It implies that each person has a hand in working towards the betterment of his or her own existence as well as the lives of future generations.

GIST Support UK & PAWS-GIST News!

By Jayne Bressington,
LRG Contributor, Vice Chair GIST Support
UK & Patient Director PAWS-GIST

The UK National Cancer Research Institute's (NCRI) annual conference was held on November 3rd-5th. This year the conference was held in Glasgow (Scotland). To celebrate the 15th anniversary of the conference, the NCRI held it's first Excellence Awards covering four categories:

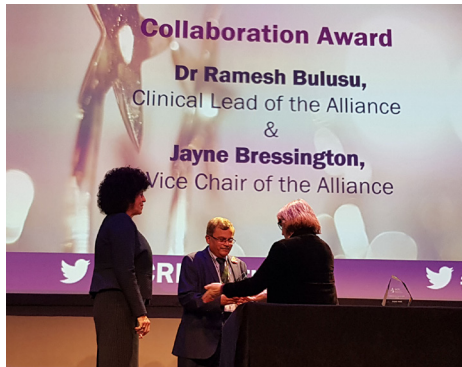
- Collaboration
- Impact
- Innovation
- Outstanding contribution

These categories are directly linked to key strategic objectives of the NCRI which aims to accelerate progress in cancer research through collaboration.

Our PAWS-GIST Alliance was reviewed by an independent panel and up against stiff competition. As a result, we are very excited to have been selected and awarded the Collaboration Award, which was presented at the conference.

Dr Iain Frame, CEO of NCRI, said:

"We are delighted to recognise and honour the achievements made by these individuals and teams who have worked effortlessly in the community to help accelerate progress in cancer research for the benefit of patients and society. We received many high-quality submissions and the panel had a tough decision to make but they felt that the shortlisted entries matched all criteria, often exceeding them."



Collaboration Award:
Jayne Bressington and Dr. Ramesh Bulusu

The conference was held over three days at the Scottish Exhibition centre in Glasgow and it was first time that GIST Support UK and PAWS-GIST had attended.

Our booth was visited by the spectrum of medical specialists and scientists which in combination with attending cutting edge research lectures and presentations has resulted in a host of new contacts and leads to progress research opportunities for GIST and PAWS-GIST cancer patients.

We are delighted to have received this award and are very grateful for



Left to right: Mathew Garnett, Jayne Bressington, Dr. Ramesh Bulusu, Richard Stephens, Paul Pharoah

the opportunities that attending the NCRI conference has opened up for GIST & PAWS-GIST patients.

From Glasgow we travelled south to Cambridge where we met with representatives from Groundwork UK and Tesco who presented us with a cheque for £10,000 which has been awarded to PAWS-GIST as a result of the "Tesco Centenary Grant Award."

This fantastic award will help to fund the next three PAWS-GIST clinics, the first of which is happening on the 28th-29th of November at Addenbrookes hospital in Cambridge.

Thank you to everyone who shopped at Tesco's over the past four months and voted for our PAWS-GIST rare cancer clinic, we could not have received this without you and as always sincere thanks to Dr. Bulusu and all of our specialists and volunteers who work tirelessly, seeking answers and opportunities to improve treatments and find a cure for PAWS-GIST!

Other awards went to: Innovation Award: *Cutting-edge work in the field of translational cancer genomics: Mathew Garnett, Translational Cancer Genomics Group Leader, Wellcome Sanger Institute*

Outstanding Contribution to the NCRI Award: *Richard Stephens, Former Chair of the NCRI Consumer Forum*

Impact Award: *for developing the Predict suite of personalised risk communication tools to help doctors and patients to make more informed decisions on cancer treatments: Paul Pharoah, Department of Cancer Epidemiology, University of Cambridge and Jem Rashbass, Public Health England*



Fatigue is one of the most common side effects among cancer patients, and can have many causes. A major factor is that some cancer treatments lower the red blood cell count, a condition known as anemia. Low blood cell production causes a lack of oxygen to be carried to the tissues, causing weakness and exhaustion. Also, the disease itself can lead to anemia. Tumors can bleed causing low blood counts and/or loss of iron. LRG patients have shared that diet and exercise can help improve their side effects. To learn more about fatigue, visit SideEQ, our personalized side effects management platform. <https://mysideeq.org>

The LRG Welcomes Newest Board Member Eric Biegansky (and Louie!)

By Laura Occhiuzzi, LRG Senior Vice President

The Life Raft Group is pleased to announce the appointment of Eric Biegansky to our Board. Eric brings his passion for supporting GIST patients and for finding a cure to his new role. Coupled with his extensive management consulting expertise and his direct experience as a GIST patient for the past eleven years, he will be an asset to our dedicated team. We are grateful Eric has accepted this call.

Eric and his family, wife Jill, son Ryan, 18 and daughter Emma, 16 (the newest licensed driver in the family), reside in the Chicago area. Not to be forgotten is Louie, their mini golden doodle, who has just also officially become a member of our LRG Board. Eric's GIST journey began 11 years ago. He has dealt with multiple surgeries and has moved through several treatment lines. Fortunately, he has been treated by one of the country's top GIST specialists. Eric has been on Stivarga for the past seven years and is stable. Through it all, he never gave up.

Eric shared that he has been questioning, "What is the point of all this? What can I do to contribute, even if it is in a small way? Should I share my own experience? How can I have an impact?"

One of the impactful ways Eric has contributed to GIST research has been the donation of his tissue to the projects of Dr. Jason Sicklick of UCSD, and Dr. Joshua Schiffman's research project at Huntsman Cancer Institute. In fact, Dr. Schiffman presented Eric with an award when they met at ASCO back in June. Eric intends to spread the message to others about the importance of patients donating tissue as a small step that can lead to a cure by advancing research efforts. He was inspired by the work of our Pediatric & SDH-Deficient GIST Consortium, which made him more passionate about giving back.

Eric recognizes that there are many ways that he can be of help to other GIST patients: Participating on GIST Chat, becoming a GIST Mentor, sharing his experience and raising awareness and funds for research. His experience in his own journey dealing with drugs and their side effects could prove valuable to other patients navigating their own path.

The LRG is excited to announce that Steve Pontell has also been named to the Board. We'll feature Steve in our next issue!



Left to right: Eric, Ryan, Jill, and Emma

...and Louie!



Update on a New Clinical Trial Offered to Eligible GIST Patients

deciphera

Deciphera Pharmaceuticals is testing an investigational drug called ripretinib (DCC-2618) as a potential new treatment option for patients living with GIST.

About Ripretinib - Ripretinib is an oral investigational drug designed to treat GISTs that are growing because of changes in specific genes. By targeting the inhibition of signals from the genes that cause cancer to grow and spread ripretinib may provide benefit to patients living with GIST.

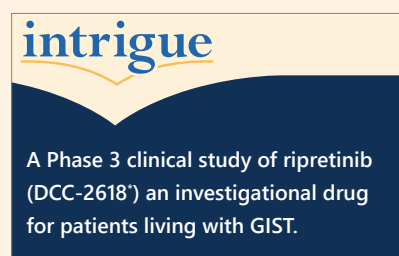
Study Overview - The INTRIGUE study is a Phase 3 clinical trial testing the investigational drug ripretinib (DCC-2618) for patients living with GIST that are no longer on imatinib due to progression or intolerance. The study is being conducted to learn more about the safety of DCC-2618 and how well it works against cancer, as compared to sunitinib (Sutent), in patients who have previously received imatinib (Gleevec). Approximately 358 GIST patients will participate in the trial worldwide. In addition to meeting other eligibility criteria, patients may be eligible to join the study if they:

- Are at least 18 years old
- Have been diagnosed with GIST and received prior treatment with imatinib only
- Are willing and able to comply with study procedures

For more information contact: clinicaltrials@deciphera.com or visit clinicaltrials.gov

Disclaimer: DCC-2618 has not been approved by the United States Food and Drug Administration (FDA) or any other regulatory agencies for sale or use by the public.

Please Note: The information (which is provided by Deciphera) contained wherein is provided solely to inform patients about the existence of this trial, and does not in any way constitute endorsement by The LRG nor is it intended to serve as medical advice. Any questions about how this trial may fit into your overall treatment plan should be discussed with your healthcare team. Sutent and Gleevec are approved for the treatment of GIST by the FDA and other regulatory bodies around the world.





Global Representative Spotlight

Amelia Yeo - Singapore

My husband Andrew and I have been together for 22 years. We thought we led relatively healthy lifestyles, so we were both shocked when he was diagnosed with GIST at 44 years of age, earlier this year in April.

Andrew experienced abdominal pain so severe an ambulance had to be called, and a CT scan at the hospital revealed a 9-cm grapefruit-sized tumour on his small intestine. The pain was caused by the tumour pressing against his intestine and causing a partial obstruction. He was operated on several days later, and 5 cm of jejunum was resected along with the tumour. Margins were clean, but he is considered high-risk due to a high mitotic rate. The tumour report revealed the mutation to be an exon 11 deletion.

I was a piano teacher and performing pianist for the past 13 years but stopped work completely this year so I could spend more time with Andrew and see to his needs.

We were so lost in the beginning because we did not know what to expect, due to the relative rarity of GISTs. We live in Singapore where there are no GIST specialists, so we could not consult with anyone in person to find out more. But thanks to the Internet, we were able to access medical websites and research papers, from which we learned about the importance of mutation testing, and that a drug - Gleevec - exists to treat this condition.

The greatest help for me though, has been finding various GIST support groups, including the Life Raft Group. Connecting with other GIST patients and caregivers worldwide has given me so much more insight as to what to expect, and how to cope with many of the challenges faced.

I am very happy to be the country representative for GIST patients here in Singapore, as I will never forget how much help I got from the various GIST networks I am now a part of. So many people can benefit from the information-sharing and emotional support these communities can offer. It is vitally important for both patients and caregivers to realize that they are not alone in this, and a wealth of information and support is available at their fingertips!

The Life Raft Group Partners with GIST Survivor on Facebook

By Diana Nieves, LRG Senior Director, Outreach & Engagement

GIST Survivor is a private group and only members can see who is in the group and what is posted. The group is for GIST survivors who are searching for a cure and living well along the way. Currently 1,235 people are members of the group and this number is increasing daily. The Life Raft Group is partnering with GIST Survivor to support the patients, caregivers, and family members affected by GIST that make up this membership.

"The goal of the GIST Survivor group is to share information related to GIST, to support one another in our journeys, and to increase the chances of us beating this disease. We are now partnering with the Life Raft Group, a non-profit organization dedicated to enhancing survival and quality of life for people living with GIST. Look for posts of support and information from their staff that will help us further our knowledge of the most current treatments, manage side effects of drugs, and help us all to live our best lives."

- Kimberly Trout Glass

The GIST Survivor group rules are:

1. Be Kind.

Share your experiences to be helpful to one another. State your opinion, but don't be rude. Please do not degrade medical professionals; they are human too, they make mistakes, and have poor judgment sometimes.

2. No Promotions or Spam

Give more than you take to this group. Self-promotion, spam and irrelevant links aren't allowed.

3. Respect Everyone's Privacy

Being part of this group requires mutual trust. Authentic, expressive discussions make groups great, but should also be sensitive and kept private. What is shared in the group stays in the group.

4. Be respectful of others

Personal beliefs may not be forced on others. Use language that doesn't offend others.

You can find GIST Survivor on Facebook:

<https://www.facebook.com/groups/43875181964/about/>



Take steps now to join GIST Chat, our new online community for GISTers and Caregivers!

We currently have a number of topics under discussion, including our members sharing their photos and GIST Stories. If you are a current ListServ member you should have received an email to join GIST Chat. The message would have come from gistchat@discoursemail.com.

If you would like to join GIST Chat and are an LRG member, please email us for an invite: mmattioli@lifaftgroup.org

If you are already a member of GIST Chat don't forget to head to forum.gistchat.org to keep up on the latest topics or even start your own.

Great News!

Recipe deadline extended for the LRG Cookbook Fundraiser

Submit your recipe by Dec 21 with this form: <https://lifaftgroup.org/cookbook-recipe-form/>

Or you can print the form and mail it to:

The Life Raft Group
Attn: Joanna O'Rourke
155 US Highway 46, Ste. 202, Wayne Plaza II,
Wayne, NJ 07470



If you have any questions or need more information, please contact Joanna: jorourke@lifaftgroup.org

Check out our events page for a Chicago Support Group meeting in January and a GISTLearn in Toronto/Kitchener, Canada.

<https://lifaftgroup.org/event/>

The LRG Calendar

GIST DAY OF LEARNING SEATTLE

Feb 15



Register: <https://lifaftgroup.org/event/gdol-seattle-2020/>

GIST DAY OF LEARNING Tampa

March 28



Register: <https://lifaftgroup.org/event/gdol-tampa-2020/>

GIST DAY OF LEARNING DENVER

May 16



Register: <https://lifaftgroup.org/event/gdol-denver-2020/>

GIST DAY OF LEARNING SAN FRANCISCO

August 29



Register: <https://lifaftgroup.org/event/gdol-sanfrancisco-2020/>



Life Fest 2020 - New Orleans

Register: <https://lifaftgroup.org/event/lifestest2020/>

The Life Raft Group Global Community

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Executive Director	Norman Scherzer
Senior Vice President	Laura Occhiuzzi
Vice President, Program Services	Sara Rothschild
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Senior Director, Outreach & Engagement	Diana Nieves
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Director, Operations	Matthew Mattioli
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Director, Outreach & Engagement	Jessica Nowak
Director, Finance	Lorraine Ramadan
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Patient Registry Supervisor	Sahibjeet Kaur
Data Analyst	Jerry Call
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Outreach & Engagement Associate	Angela Edson
Patient Registry Associate	Stephanie Gachette
Patient Registry Associate	Jennily Eshak
Marketing & Operations Associate	Jayda Jones
Outreach & Engagement Associate	Joanna O'Rourke
Project Coordinator	Helena Mattioli
Executive Assistant	Allison Russo
Consultants	
Global Relations Coordinator	Piga Fernández
Grants Consultant	Kathleen Gronet
IT Consultant	James Lee

LRG Volunteers

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Official Greeter	Gail Mansfield
Clinical Trials Coordinator	Jim Hughes
Staff Photographer	Michelle Mattioli
General Counsel	Steven Pontell
State Liaisons	Charles Burke
	Rick Isaías
Science Team	Erin MacBean
	Paula Vettel
	David Josephy
	Michael Josephy
	Joan Krakowsky
	Jim Hughes
National GIST Mentor Director	Santy DiSabatino
GIST Mentors	Julie Durkee
	Eric Lindberg
	Karen Meyers
	Marlene Nei
	Kay Stolzer
	Rob Taylor

Board of Directors

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Stan Bunn – Past President
Gary Glasser – Secretary/Treasurer
Jim Hughes
Teena Petersohn
John Poss
Rodrigo Salas
Eric Biegansky
Steve Pontell
Mia Byrne (Ex Officio)
Ray Montague (Ex Officio)

Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director, Outreach & Engagement
dnieves@lifteraftgroup.org

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior VP
locchiuzzi@lifteraftgroup.org

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Life Raft Regional Chapters Find info for a local & global reps at lifteraftgroup.org/find-a-support-group/

Alabama	Kyle Brown	Maine	Jodi Merry	Puerto Rico	Eileen Rolon
	Gina Smith	Maryland	Wendi Lax	South Carolina	Paula Stover
California, Northern	Martha Zielinski	Michigan	Ellen Rosenthal	Tennessee	Alice Sulkowski
California, Southern	Dina Wiley	Michigan - West	Cliff Kopp	Texas	Dee Hawkins
Colorado	John Abrams	Minnesota	Tom Dupont	Utah	Mike Ginsberg
	Donald Hurd	Missouri	Katie Bloss		Carrie Callister
Delaware	Cindy Bones	Nevada	Joan Smith	Vermont	Elizabeth Ching
Florida	Marian Ritter	New Hampshire	Jenna Colby	Virginia	Sally Jackson
Hawaii	Erin Rakes	New York	Pat Bonda-Swenson	Washington	Jack Tinnea
Idaho	Janet Conley		Frances Wenderoth	West Virginia	Susan Caperton
Illinois	Jim Hughes	North Carolina	Jennifer Higgins	Wisconsin	Rick Ware
	Marlene Nei		Carolyn Dewalt	Wyoming	Alan Quille
Iowa	Barbara Kepple	Oklahoma	Jane Rowan	At Large	Charles Burke
Kansas	Christine Engel	Pennsylvania	Jeffrey Bernstein		
			Tiffany Werner		

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Life Raft Global Liaisons See global news & resources in our **International section** on our website.

Argentina	Mariel Garibaldi	Hong Kong	Thomas Chow	Poland	Piotr Fonrobert
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Austria	Amy Bruno-Lindner	India	Nikhil Guhagarkar	Russia	Dmitry Bukhtenkov
Belgium	Gerard van Oortmerssen	Iran	Negar Amirfarhad	Samoa	Leasi John Galuvao
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Brazil	Luciana Holtz	Italy	Barbara Tamagni Colombo	Scotland	Stacey McAully
Bulgaria	Juliana Popova	Japan	Sumito Nishidate	Singapore	Amelia Yeo
Canada	David Josephy	Jordan	Sameer Yaser	Spain	Luis Herrero
Chile	Piga Fernández	Kenya	Florence Thwagi	Sudan	Mohamed-Elbagir Ahmed
China	Minying Zheng	Macedonia	Dejan Krstevski	Switzerland	Helga Schnorf
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