

Ensuring no one has to face GIST alone

In Loving Memory: Paula Vettel, Christopher Loines, Bob Kinsey, Carlos Narbona, John DeJong, John Kirk

Rare Diagnosis Fosters a Passion for Biomarker Testing & Self-Advocacy

#TimeToGetTested

by Carolyn Tordella, LRG Assistant Director Communications

It's become a June tradition to promote patient stories that epitomize hope (#GISTHope). With the transition of spring into summer, and all the activities this season entails such as GIST Awareness Day, Sarcoma Awareness Month, and the GIST DO IT Walks, what better season to spread hope through stories of GIST thrivers?

This year the LRG has expended a tremendous amount of energy emphasizing the importance of biomarker testing through our It's Time - Biomarker Testing Campaign which focused on twelve key points that illustrate how testing affects overall patient survival. We want to improve the statistics that show that in the general population less than 30% of GIST patients get mutational testing. Our goal is to ensure that all GIST patients get advanced testing to ensure that they are guided to the most effective treatment for their mutation. Specifically, this means going beyond basic testing to confirm a GIST diagnosis. While around 80% of GIST patients may test positive for a more common mutation, for example exon 11, which typically is very responsive to Gleevec, a smaller population will have a mutation such as SDH-deficient GIST, NF1, or BRAF, for example. Rarer mutations are not responsive to imatinib, sunitinib, or regorafenib (approved 1st - 3rd line treatments.)

In this featured patient story GISTER Bill Borwegen of Maryland shares how knowing

his mutation affected his treatment options and why knowing his mutation sooner rather than later could have affected his outcome severely. Bill's GIST journey began in March of 2018 at 62, when fatigue, severe anemia, and bleeding drove him to the doctor and subsequently the hospital. His primary physician wanted Bill to receive a pint of blood but even with a low blood count, the hospital refused. In the midst of his first self-advocacy challenge, he underwent an EKG and bloodwork. He commented on that situation:

"I sat in the emergency room of my local hospital getting weaker and weaker and they wouldn't give me the pint of blood that my doctor sent me over to get. I knew that I had to take matters into my own hands and fight for myself. Doctors are very smart and dedicated, but you can't just rely on what they tell you. You need to do your own due diligence and do your research."



Bill Borwegen, son Luke, and wife Jane.

THIS ISSUE

New Board Members	3
Advocacy in Mexico	6
Medical Advisory Board	8
SDH Consortium Update	10
Meeting Notes	11
New Global Rep - India	12
GIST Awareness Day Ideas	13

Bill Borwegen's story continues on page 4

The Room Where It Happens

It is hard to believe that it has been 20 years since the discovery of imatinib, the first oral targeted chemotherapy drug that ushered in the era of precision medicine. Like the song from the popular musical Hamilton states, the Life Raft Group was "In the Room Where It Happens."

Sometimes there is a confluence of events that profoundly affect both individual lives and the lives of society in general. You can call it fate, or if you are religious, the work of a higher power. Perhaps it is just serendipity, but for the LRG, it was the beginning.

My personal mission twenty years ago was to save my beloved wife Anita's life. She had been given a death sentence when a series of fortunate events and a cast of diverse characters came together at precisely the right moment.

Who could have imagined that the work of a biochemist (Nicholas Lydon), a researcher (Brian Druker); a brave head of a pharmaceutical company who pushed forward the development of a drug for a rare disease market plan, choosing to follow the science (Dan Vasella, former CEO of Novartis); and the inspired creator of ACOR and its online support communities who provided a lifeline for patients (Gilles Frydman) would lead to the LRG patient scientist/advocacy movement that saved so many lives?

The Life Raft Group has had its own share of these lucky coincidences: A former editor of a major newspaper taking over the helm of our little newspaper, my early belief that data matters, starting with index cards on my living room rug leading to our sophisticated cloud-based Patient Registry; a friend who put me in touch with the email for the head of Novartis Pharmaceuticals and the strong bond Dan Vasella and I developed, saving hundreds of lives. It has taken us from a lunch with a Nobel prize winner (James Watson), to sharing a podium with Senator Ted Kennedy, and more recently, spending time with the current President of the United States, Joe Biden when we were invited to be a part of the Biden Cancer Initiative.

Anita's life and the lives of countless others were extended because science and determination came together with a common goal.

We continue to be in "the room where it happens" through our global collaborations, including aiding the National Institutes of Health by hosting a virtual Pediatric & Wildtype GIST clinic in lieu of their annual in-person event. Our Global Surveillance Group is at the ready when physicians from India to Portugal call seeking help when patients need it most.

Our focus for the past twenty years has not waived - to improve the survival and well-being of GIST patients. We will continue to be "in the room," and actively take a seat at the table to achieve these goals.

- Norman J. Scherzer

Celebrating Our Newest Board Members!

"I am excited, and, frankly humbled, to announce the expansion of our Board of Directors. As our organization grows and our patient population grows, so does the need to continue to expand our Board. It is with great excitement that I welcome Dr. Monica (mOe) Anderson and Kay Stolzer as our newest Board Members. She is a motivational speaker, author and fellow GISTer and has been a tremendous supporter of the LRG. She recently moderated our Women in Sarcoma Gala and has been a speaker at our educational events. Dr. mOe has a heart for inspiring others and we look forward to seeing her in action as she helps us achieve our goal of supporting every patient and caregiver with GIST. Kay Stolzer is an extraordinary advocate for GISTers. Kay says she loves to connect with patients one-on-one and that comes through in all she does. Kay is a GIST mentor, has volunteered on our insurance committee, and is moderating our Women's Support Group series. She has gone above and beyond already and we are excited to see her continue to expand her role in our GIST community."

– Jerry Cudzil, LRG Board President



Kay Stolzer has been very active in our LRG community as a volunteer, currently as a GIST Mentor and formerly as a participant of our A3 Insurance Committee. Kay has a tremendous amount of past experience working as a business administrator. She is now the facilitator of our patient

support group, "Living Well with GIST: A Monthly Support Group for Women." Kay enjoys spending time with family in New Jersey and Tennessee.

Dr. Monica Anderson, or Dr. mOe as she is known to her fans, is an inspirational leader who resides in Texas. Dr. mOe has spoken at Life Fest 2016, served as a spokesperson for our holiday campaign, and was the emcee at the 2020 Women in Sarcoma Gala which honored women who have made an extraordinary impact on the lives of sarcoma patients. Dr. mOe is a dentist, author, speaker, and podcaster. She has served as a board member and volunteer to several nonprofit organizations and has a wealth of knowledge as a business owner and as an executive of a publishing company and has a passion to raise awareness about GIST.



GISTMENTOR EXPANSION

We are excited to announce that the LRG recently expanded its GIST Mentor program to include nine global volunteers from Austria, Canada, India, Kenya, and Singapore. On Wednesday, June 9th, volunteers were trained by Piga Fernández, our Global Relations Consultant and Global GIST Mentor Director, and Diana Nieves, Senior Director, Outreach and Engagement.

The GIST Mentor program began in the Spring of 2019 and since then, the program has grown to 25 mentors who are servicing almost 200 mentees. The mission of The Life Raft Group's GIST Mentor Program is to support people with GIST and their loved ones as they navigate through diagnosis, treatment, and recovery. The program exists to help patients and their caregivers advocate for themselves and provide emotional support as they continue their journey with GIST.

An LRG GIST Mentor is a survivor or caregiver who can offer you understanding and empathy. GIST Mentors reassure patients and their caregivers that they are not alone in their GIST journey. This program is available to patients, caregivers, family members or a close friend of a GIST patient for support during this difficult period.

If you are interested in becoming a GIST Mentor, please contact Diana Nieves at dnieves@liferaftgroup.org



Bill enjoying one of his other passions - sailing.

During the next two months, Bill was tested and monitored (endoscopy, colonoscopy and bloodwork), and then had a CT with contrast which revealed a mass and in June of 2018 his surgeon performed a resection of the jejunum. Initial pathology confirmed

GIST with a low mitotic rate.

The tumor was 3.1 cm and

removed with clear margins. In August, after a period of healing from the surgery, his local oncologist and his surgeon agreed that Gleevec was the correct treatment path but Bill's side effects stopped him from being satisfied with that solution.

Bill's system didn't tolerate Gleevec well. He was resistant to the idea of continuing to take the drug treatment though he complied for about three months. After attending a GIST conference at MD Anderson, he vehemently believed that mutational analysis was necessary. He had to insist that mutational testing was done. He received those results and after consulting with his oncologist, it was decided that Bill would discontinue Gleevec since his testing revealed a somatic NF1 mutation which is not responsive to Gleevec.

"You have to be your own patient advocate. I was having a hard time tolerating the Gleevec. If I hadn't insisted on mutational analysis, I might still be on Gleevec," said Bill about this experience. He continued, "I had to literally demand mutational testing which is kind of crazy if you think about it. I can understand starting with Gleevec but I would think they would simultaneously order the mutation testing but they didn't do that so I did my own research and I said that I wanted the mutational analysis. I stopped taking the Gleevec eventually myself, which I wouldn't recommend, because of how badly I was feeling. Of course, if you have the mutation that will respond, you'd look at these side effects differently and adjust."

Bill also decided to find another care team. He is of the opinion that if your oncologist has an issue with the idea of a second opinion or a collaboration "you need to not walk. but run." The GIST specialists that he's dealt with have had none of those 'pride of ownership' ego issues but have been eager for collaboration. Bill was reassured to know that his current oncologist has this collaborative relationship with 30 experts who work together (the LRG Project Surveillance Group and the Pediatric & SDH-Deficient GIST Consortium via virtual tumor boards

and email discussions) and if there is a recurrence in the future, he's in good hands. He's had conversations and consultations with several GIST experts including Dr. Jonathan Trent (Sylvester Comprehensive Cancer Center, Miami), Dr. Margaret von Mehren (Fox Chase Cancer Center, Philadelphia), Dr. John Glod (National Institutes of Health), Dr. Jason Sicklick (Moores Cancer Center, San Diego) and Dr. Michael Heinrich (OSHU, Oregon). All of whom Bill says have been very accommodating in answering all his questions about his very rare form of GIST.

Currently not on medication and showing no signs of recurrence thus far, Bill is spending his retirement years sailing, hiking, consulting for his last employer and volunteering. He has helped restore and now is a docent for the Thomas Point Shoal Lighthouse, the last original screw-pile lighthouse still in operation and takes tours out on skipjacks, boats historically used for oyster dredging. He and his wife enjoy sailing with their two grown sons and love the outdoors. Surveillance of his condition at this point is simply scans every year - wait and see - so far he is NED (no evidence of disease). Though

he's confident that his team of experts will be there for him in case of a recurrence, he feels it's a good idea to stay current on what's happening in the world GIST and NF1 research. "They just don't know enough about this very rare form. There's not enough epidemiology out there yet." He's hopeful that new targeted therapies will be available if and when it may be necessary.

His advice for newly diagnosed GIST patients:

"I definitely recommend that every GIST patient find a GIST specialist. There are just too many cancers out there for every local oncologist to have a lot experience with something as rare as GIST. I try to read all the technical papers. Ideally your GIST specialist will be one of the people that has written one of these papers. My own oncologist attends the annual sarcoma meetings. If you're going to continue to see your own oncologist then you should also see a GIST expert and if you don't you could run into a lot of trouble - like taking a drug



The Thomas Point Shoal Lighthouse

Bill Borwegen's story continues on next page

Bill Borwegen's story continued from page 4

for years that isn't helping. And it's a great expense. Gleevec - \$27,000 for a three-month supply. Worrying about drug cost as well as the disease itself is really more than anyone should have to put up with when dealing with cancer."

Bill encountered the Life Raft Group during his research on the web and said, "I was so grateful that there was such a team of bright, dedicated professionals that cared so greatly about this disease and provided support to patients and who work with the leading researchers not only in the country but around the world. I knew that I needed to learn more about the organization and I also wanted to know how I could support and help the LRG to continue their important

lifesaving work." Bill has been an enthusiastic volunteer and supporter of our mission.

Bill feels strongly about education and awareness for medical professionals too. "There needs to be an editorial or something in medical journals. Mutational analysis needs to be common practice. It's not an option. It's the most important thing to have after the details of the tumor itself, like size and mitotic rate. And if your oncologist gives you any push back, run, don't walk, to a GIST specialist."



It's Time!

Understanding the role of mutations and biomarker testing is one of most important things patients must learn. Uncovering

the driving force behind each individual's tumors is not just important, it is critical. Biomarker testing is an opportunity to improve and optimize treatment - possibly avoiding unnecessary treatments and getting to the right treatment sooner. Our **Biomarker Testing Campaign** has a goal to get all GIST patients to be

aware of this important tool for their treatment path and get tested. For more information on advanced testing, visit this link:

liferaftgroup.org/timetogettested



I think the Life Raft Group is a wonderful organization. It makes patients feel less hopeless and that there are people who care..

- Jane E. Foster



GIST PATIENT REGISTRY

Patient Registry Data

2340
members



52%
female



48%
male

53% of members know their mutation

Our goal is that ALL GIST patients have biomarker testing in order to more accurately inform treatment decisions.

If you do not know your mutation or have not had mutational testing (a type of biomarker testing), we can help! Please email dmontoya@liferaftgroup.org

The Eyes Don't See What the Mind Doesn't Know

by Rodrigo Salas & Berenice Carbajal-López



Fundación GIST
México

As you know, GIST is a rare disease, and the outcome of the patient's treatment depends on a correct and prompt diagnosis and treatment selection by the oncologist.

In Mexico, there are an estimated 2,000 new cases of GIST every year. At Fundación GIST México we are committed to ensuring the survival and quality of life for these patients.

One issue we faced in Mexico was that there were very few GIST patients diagnosed in cancer centers in our country. There are several reasons for this. An important one is that the symptoms of GIST are not specific. When a patient begins to experience them, they never go directly to an oncologist, they would go to a family doctor, or if they live in a small town or in the mountains, they would go to whomever is available, sometimes a pharmacy doctor. Since GIST is a rare disease, it is not known by most doctors who are not oncologists, so they normally give the patient treatment for gastritis or other diseases, and it is not until they are really sick that they may go to a specialist.

That was the main problem we found in our country. Someone once said that "you can not suspect what you don't know, and you cannot diagnose what you do not suspect". In light of this, we created a program named "Saving Lives through Education" to promote timely diagnosis by training the medical



community about GIST. This program began in 2011 with the collaboration of Monterrey Tec, one of the finest universities in Mexico. At first, this 20-minute educational program was only aimed to contact physicians. The program was uploaded on a platform, and the idea was to make it available to doctors so they could educate themselves.

With the help of the Life Raft Group, we contacted a pharmaceutical company, and explained the aim of the program. The idea was to let them promote the project among the doctors they visited. We tried this for a couple of years without success and then we moved on to a totally different approach. We began going to the hospitals contacting the professor in charge of the educational programs for physicians in order to ask them to present our program in their "plenary sessions," allowing us connect with a larger number of physicians and leave them no option but to learn about GIST. This method seemed to work very well, resulting every year in a higher number of physicians trained in GIST diagnosis and treatment.

Then we realized a considerable number of patients lived in cities and towns far from big hospitals, and we just couldn't go to every town or every small city to get doctors trained. We realized the perfect idea was to train medical students - those that study in the cities and who would eventually be the doctors in all these small towns. The program for students was a little bit different. We included dynamic presentations, games, and even some contests to reinforce the knowledge and raise awareness about GIST.



As of today, with the voluntary help of certified oncologists, we have educated more than 7,000 doctors with the following specialties: Internal Medicine, General Surgeons, General Physicians, and Gastroenterologists. We have trained more than 14,700 students in GIST diagnosis and treatment.

We are now seeing more and more GIST diagnoses in our country every year. We try to update those who participate in our program with an "UpToDate GIST" which is a weekly newsletter delivered by email.

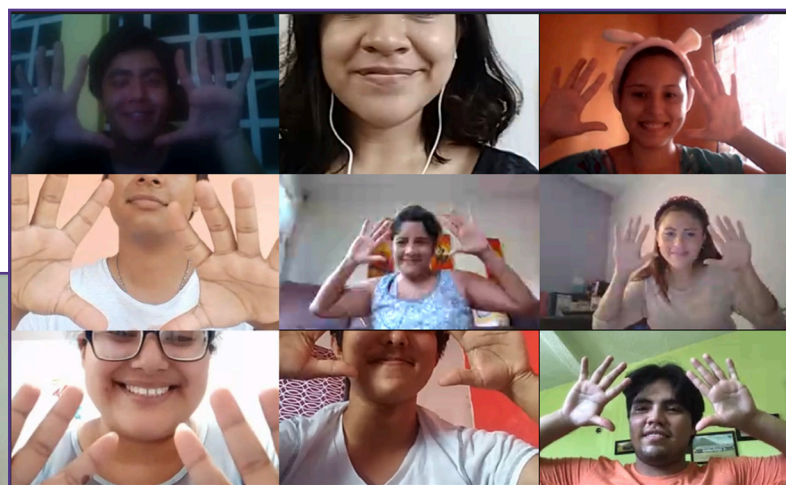
Also, thanks to this program, our number of volunteers has increased dramatically. Our volunteer program has registered around 130 GIST volunteers, most of them being medical students located throughout Mexico. They donate their time and knowledge to GIST patients, participating in educational programs for patients, GIST videos, and other activities.

Since the pandemic began, we have not been able to travel to hospitals and gather doctors together to take the course. We have, however, been able to reach medical students through Zoom meetings successfully.

Through this journey, we have learned that not only is the clinician's job fundamental for GIST patients' survival, but also that the pathologist's job is very important. The characteristics to be evaluated when examining a GIST tumor will allow the clinician to establish the risk of progression and to make therapeutic decisions, thereby increasing treatment response and ultimately saving the lives of GIST patients.



This is why we have collaborated with Dr. Monica García-Buitrago, who is an expert pathologist from the Sylvester Comprehensive Cancer Center in Miami, in developing a program in Spanish to educate Latin American 'PatholoGISTs' entitled "Update in Histopathological Criteria for the Diagnosis of GIST". With the help of Dr. García-Buitrago, we aim to raise awareness among pathologists and share with them how important their job is in saving GIST patients' lives. We plan to launch this program in Latin America through AlianzaGIST, a coalition of GIST patient organizations in our region.



<http://fundaciongist.org/>
fundaciongist@gmail.com

For more resources in Latin America & around the globe, visit the International section of the Life Raft Group website.

Dr. Michael C. Heinrich

Knight Cancer Institute,
OHSU School of Medicine
Portland, Oregon

Dr. Heinrich is a medical oncologist at the Knight Cancer Institute and Professor of Medicine and Cell/Developmental Biology at Oregon Health and Science (OHSU) School of Medicine. His research, like much of the work at the Knight Cancer Institute, revolves around a basic, yet complex premise. You have to understand what is broken in order to fix it. That's why Dr. Heinrich is intently focused on identifying the molecular targets that cause cancer, which is essential to the development of better and less toxic therapies. He is recognized internationally for groundbreaking research discoveries that have improved care for patients with gastrointestinal stromal tumors, and his research has implications for many types of cancer.

Dr. Heinrich's research includes both preclinical identification of novel molecular targets and testing of new agents in the laboratory and the clinic. This includes both genomics research using high-throughput genotyping to identify oncogenic mutations and testing of new compounds in cellular and biochemical assays. His laboratory is particularly expert in the analysis of inhibitors of oncogenic receptor tyrosine kinases such as KIT, PDGFRA and FLT3.

Dr. Heinrich earned his medical degree in 1984 from Johns Hopkins University School of Medicine in Baltimore. He completed both his residency training and hematology and medical oncology fellowship at OHSU.

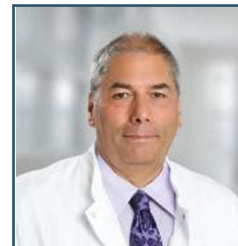
Dr. Sameer Rastogi

All India Institute of Medical Services,
New Delhi, India

Dr. Rastogi is a faculty member in the Department of Medical Oncology at All India Institute of Medical Sciences (AIIMS), New Delhi, a leading tertiary care center in North India. Currently, he is running a dedicated sarcoma and gastrointestinal stromal tumor (GIST) medical oncology clinic in AIIMS New Delhi. His other interests are endocrine cancers and melanoma.

Over the years he has gained extensive experience with GIST and has many GIST patients on treatment currently. His areas of interest are mutational testing in GIST, wildtype GIST and newer medicines including avapritinib and ripretinib. A group of patients who received treatment from him have formed a sarcoma support group called Sachin Sarcoma Society which is currently one of the leading support groups for sarcoma/GIST patients in India.

Dr. Rastogi did his Medical Oncology fellowship at Tata Memorial Centre, Mumbai and has various publications to his credit including articles in prestigious journals. He has received various international awards like the Young investigator Award from SIOP (International Society of Pediatric Oncology) and the Clinical Oncology Society of Australia (COSA) Asia Pacific award.

Dr. Peter Reichardt

Helios Klinikum
Berlin-Buch
Berlin, Germany

Dr. Reichardt is the Assistant Professor and Head of the Department of Oncology and Palliative Care at the Helios Klinikum Berlin-Buch in Berlin, Germany, and is the Director of the Cancer Center Berlin-Buch and the Sarcoma Center Berlin-Brandenburg.

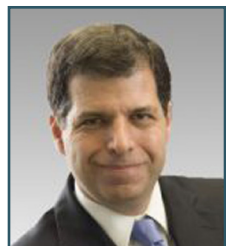
Dr. Reichardt has led and conducted multiple clinical trials in bone sarcomas, soft tissue sarcomas and gastrointestinal stromal tumours in the adjuvant, advanced, and refractory settings.

Dr. Reichardt is a co-author of the current European Society for Medical Oncology (ESMO) guidelines for the management of GIST, soft tissue and bone sarcomas and a member of the ESMO Sarcoma Faculty. He is Chairman of the German Sarcoma Foundation, a member of the Medical Board of the MAX Foundation, and a member of the Life Raft Group's Global GIST Advisory Team. Dr. Reichardt has contributed to numerous publications on soft tissue sarcoma and GIST management in leading oncology journals.

He trained in internal medicine and haematology/oncology at the University of Heidelberg and at the MD Anderson Cancer Center, Houston, TX, USA. From 1992 to 2007, he was a consultant at the Charité University Hospital in Berlin.

The Life Raft Group is pleased to present the members of the LRG 2021 Medical Advisory Board. Members will play a crucial role in offering expert opinions on research and medical developments. Comprised of experts from leading academic and medical institutions around the world, the goal of the Medical Advisory Board is to share scientific and research expertise to provide strategic direction on LRG initiatives that ensure the overall survival and well-being of gastrointestinal stromal tumor (GIST) patients.

Dr. Gary Schwartz



Herbert Irving
Comprehensive
Cancer Center
Columbia University,
NYC

Dr. Schwartz is a board-certified medical oncologist and internist and chief of Columbia University Medical Center's Division of Hematology and Oncology.

He is actively involved in translational and clinical research. The lab, which he directs, focuses on the identification of new targeted agents for cancer therapy, especially in the treatment of sarcoma and melanoma. However, these agents are not disease specific and hold promise in the treatment of all solid-tumor malignancies. These laboratory studies allow for a bridge between the laboratory and the clinic, and many of these drugs that originated in the lab are now being evaluated in clinical trials. His research studies have been supported by the National Cancer Institute, the Lustgarten Foundation for Pancreatic Cancer, the Department of Defense for Breast Cancer Research, the Byrne Foundation, and the Food and Drug Administration. He is involved in the teaching and mentorship of junior faculty and fellows, and he takes great pride in his active participation in patient care.

Dr. Schwartz has also served on the editorial boards of a number of scientific journals, and as associate editor on both the Journal of Clinical Oncology and Clinical Cancer Research. He is the author of nearly 200 papers and 17 book chapters and is a graduate of Albany Medical College Medical School.

Dr. Jason Sicklick



Moore's Cancer
Center, UCSD
San Diego,
California

Dr. Sicklick is an NIH and FDA R01 funded investigator, Professor of Surgery, Executive Vice Chair of Research in the Department of Surgery, and Co-Leader of the Sarcoma Disease Team at Moore's Cancer Center UC San Diego Health

He is a board-certified general surgeon and surgical oncologist specializing in the treatment of complex retroperitoneal and abdominal sarcomas, including gastrointestinal stromal tumors (GIST), as well as hepatobiliary oncology.

Dr. Sicklick is an active member of the National Comprehensive Cancer Network (NCCN) Soft Tissue Sarcoma Committee and GIST Subcommittee, and the Trans-Atlantic Australasian Retroperitoneal Sarcoma Working Group, amongst 11 national/international committees he currently serves on. Dr. Sicklick is on the Editorial Boards of Annals of Surgical Oncology, Journal of Gastrointestinal Surgery and Journal of Surgical Research.

He received his medical degree from the UCLA School of Medicine, completed his general surgery residency at The Johns Hopkins Hospital where he was the Administrative Chief Resident, and completed a fellowship in surgical oncology at Memorial Sloan Kettering Cancer Center where he was the Chief Administrative Fellow. He joined the UC San Diego Division of Surgical Oncology at Moore's Cancer Center in 2010.

Dr. Jonathan Trent



Sylvester
Comprehensive
Cancer
Center, University
of Miami
Miami, Florida

Dr. Trent is the Associate Director for Clinical Research, the Director of the Bone and Soft-tissue Sarcoma Group and Medical Director of the Precision Medicine Initiative at the Sylvester Comprehensive Cancer Center at the University of Miami Miller School of Medicine.

The major focus of his clinical, educational and research efforts are with gastrointestinal stromal tumor (GIST), chondrosarcoma, and other sarcomas. The major efforts of Dr. Trent's research focus on understanding the mechanisms of action and resistance of imatinib in GIST and other sarcomas while striving toward improved therapeutic options. His work involves the use of novel preoperative/postoperative clinical trials, prospectively acquired tumor tissue, cell lines, archival tissue, as well as collaborations with disciplines such as the genomics facility, surgical oncology, pathology, radiology and interventional radiology.

Dr. Trent earned his MD and PhD in cancer biology from The University of Texas Health Science Center where he also completed a residency in internal medicine. He then completed a fellowship in medical oncology at The University of Texas MD Anderson Cancer Center while serving as chief fellow. Prior to joining the University of Miami, Sylvester Comprehensive Cancer Center, he held an appointment as associate professor of medicine at the University of Texas MD Anderson Cancer Center in Houston.

Please note: At the time of this announcement in March, Dr. Suzanne George was included on this list. Dr. George has since withdrawn due to scheduling conflicts. Another candidate(s) will take her place in the future.

Update on Our Pediatric & SDH-Deficient GIST Consortium

by Sara Rothschild, VP Program Services

On May 3rd, Dr. Andrew Blakely, surgical oncologist with the National Institutes of Health (NIH), presented information to the Consortium about his latest trial at an April meeting of the Pediatric & SDH-Deficient GIST Consortium. This study is titled: Surgery in Gastrointestinal Stromal Tumors (GISTs) for Treatment, Tumor Modeling, and Genomic Analysis NCT04557969 - A Prospective Observational study that will monitor GIST patients long-term pre- and post-surgery.

Both wildtype and non-wildtype patients are eligible for this study. The objective is to get more tumor tissue to support translational analysis to help with PDX (patient derived xenograft) models¹, cell lines, organoids, and preserved tumor micro environments for ex-vivo investigation.

All participants are in 1 cohort/1 arm. Everyone undergoes the same protocol regardless of their type of GIST. Participants will be monitored every six - 12 months at the NIH Clinical Center, for up to 10 years before having surgery. If they need surgery, it will be performed at the NIH. Then, they will be monitored every six -twelve months, for up to 5 years after surgery. With surgery, tumor tissue samples will be taken.

If a participant does not need surgery, their participation will end after 10 years. If they have surgery, the five-year monitoring period will restart after each surgery. Surveillance can also be done locally. The NIH will offer patients next generation sequencing (NGS) and support in translational initiatives. Protocol details are listed at the [ClinicalTrials.gov](https://clinicaltrials.gov) for NCT04557969.

This trial is exciting because patients who may be at stage 4 disease can consider going there for surgery (even to debulk liver). Additionally, international or non-insured patients are eligible to join study as care is covered at NIH. Transportation to and from the NIH is not covered and post-discharge care is not covered by NIH. The NIH has been able to do more virtual visits due to new standards set during the covid pandemic and patients can upload their scans into the NIH system.

The concept of the study is to preserve tumor tissue and tumor micro-environment for further investigation. Dr. Blakely will perform live tumor imaging using a custom 3D printed platform. He will also evaluate biomarkers and look at therapeutic agents to test on tissue. Overall, this is a good platform to test drug candidates.

The meeting concluded with great collaboration prospects among the various global medical institutions regarding sharing of tissue and datasets – all of which foster our ultimate goal for the Pediatric & SDH-Deficient GIST Consortium.

¹ PDX models mostly retain the principal histologic and genetic characteristics of their donor tumor and remain stable across passages. These models have been shown to be predictive of clinical outcomes and are being used for preclinical drug evaluation, biomarker identification, biologic studies, and personalized medicine strategies. ([Hidalgo, et. Al., Patient-derived xenograft models: an emerging platform for translational cancer research, Cancer Discov. 2014 Sep;4\(9\):998-1013. doi: 10.1158/2159-8290.CD-14-0001. Epub 2014 Jul 15. https://pubmed.ncbi.nlm.nih.gov/25185190/](#))



Dr. Andrew Blakely
Program Director,
Surgical Oncology
Research Fellowship,
NIH

**Find More SDH-Deficient GIST Information
& Support on our website:**
<https://liferaftgroup.org/sdh-deficient-gist/>

“ #GIST
HOPE

I have a lot to be grateful for. Because of LRG, I have my life back and have it in a brighter way. The LRG Team aggressively and compassionately helps those who were like me, lost. I am extremely grateful.

- Rob Taylor

”

Notes About Southern California's Support Group Meeting in April

In April, the Life Raft Group hosted a virtual support group. It was an informative Saturday afternoon for GIST patients and families who gathered via ZOOM. In attendance were Dina Wiley, Southern California's Group Leader, Laura Occhiuzzi, Senior Vice President of The Life Raft Group and Diana Nieves, Senior Director of Outreach & Engagement.

Dina was quick to make everyone feel warmly welcomed. Her motto is "Helping Others with Gastrointestinal Stromal Tumor". We were very fortunate to have Dr. Jason Sicklick of UC San Diego Moores Cancer Center join us as the participating physician in attendance for this support group meeting. He is a surgeon and scientist who is truly dedicated to GIST patient care and deeply committed to moving GIST research forward. In addition to his GIST expertise, Dr. Sicklick has special expertise in the rarer subset of GIST, including SDH-deficient GIST. He is also a founding member of The Life Raft Group's Pediatric & SDH-Deficient GIST Consortium.

In 2016, Dr. Sicklick was awarded The Life Raft Group's GIST Clinician of the Year award. In 2018, Dr. Sicklick was honored with Global Genes RARE Champion of Hope in Medical Care and Treatment Award. Most recently, the National Organization for Rare Disorders



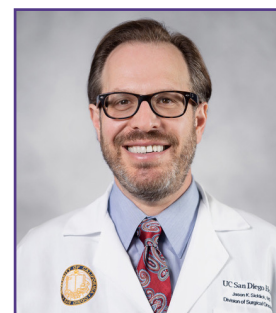
by Debra Melikian

LRG Contributor, GIST Patient Advocate & Caregiver
Debra is a 'mother on a mission' to raise awareness and financial support for GIST Cancer Research.

(NORD) announced they will be honoring him as a hero in rare disease with their prestigious Rare Impact Award 2021 on June 28th, 2021.

During this two-hour support group meeting, GIST patients and their families shared their experiences, and listened intently, as well as posed thoughtful and thought provoking questions. Dr. Sicklick engaged the audience, generously shared his depth of knowledge, gave clarity, understanding and provided reassurance to GIST patients and families. The attendees discussed the spectrum of GIST from localized disease to metastatic tumors emphasizing the importance of mutational testing. He also briefly shared about current research he and his lab team are conducting as it related to some of the questions that were posed.

Sincere thanks to Dr. Sicklick for participating in this Support Group meeting and for all that he does every day, for GIST patients near and far.



Dr. Jason Sicklick

The LRG Adds to Virtual Support Group Offerings

Living Well with GIST: A Support Group for Women, was formed to create a safe space to discuss how this diagnosis, treatment and other issues uniquely affect women. Our hope is that the journey will be made a little easier with the support of others with similar experiences.

Our monthly support group began on Saturday, March 27th, with 26 women participating. Introductions were made and stories were shared. In addition to Diana Nieves, Laura Occhiuzzi, and Jessica Nowak, members of the LRG staff, in attendance was our first guest

Living Well with GIST: A Support Group for Women

Last Saturday
of Each Month
1:00 PM - 3:00 PM ET



by Kay Stolzer

LRG Contributor, GIST Mentor & Support Group Leader

speaker, Sandra Brackett, a nurse practitioner at Ronald Reagan UCLA Medical Center, who sees many GIST patients. Sandra answered several questions regarding treatment and side effects from the group.

Berenice Carbajal of Fundación GIST México was our guest speaker during our second meeting on Saturday, April 24th. Berenice is a nutritionist, who has spent her career studying how best to help GIST patients affected by medication and surgeries, and how that impacts their ability to absorb nutrients. This information was invaluable, as so many GISTers struggle with diet and medication.

At our next meeting on May 29th, we shared our experiences, issues, and most importantly, discussed what the participants wanted to see in our support group sessions.

If you are interested in learning more about this or our other support groups, please contact Diana Nieves at dnieves@liferaftgroup.org to learn more.

Spotlight on LRG Global Representatives

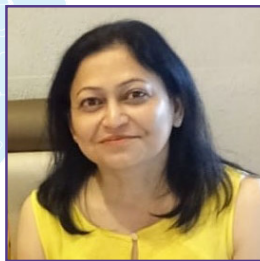
The newest GISTer to join the ranks of LRG Global Representatives is Nandini Dabbir of Hyderabad, India. Living with GIST since 2007, Nandini is also a survivor of papillary carcinoma of the thyroid, which was diagnosed in 2003. She is a the Friends of Max City Chapter Leader & GIST Advocate working with the LRG to support GIST patients on their journey.

"Being diagnosed with cancer will in all probability come as a shock to most patients and my journey is a testament to this. What helped me overcome this reality was to always have a positive outlook and hope for a better tomorrow. I suggest the same to everyone who is going through this difficult phase. Surround yourself with the people you love the most and be cheerful because this hard time shall pass." Nandini shared.

Our new representative has a quite a bit of experience working with people. An administrator professionally, she has honed her people skills volunteering for many years teaching English to underprivileged children. Most of 2020, due to the pandemic, she met with her students one-on-one online. Nandini has also been very active in an international women's organization known as the Inner Wheel Club, a group which promotes friendship and service across different countries of the world - "helping those in need and working toward the betterment of society".

She credits her internet research for finding Dr. Sameer Rastogi, a GIST specialist in New Delhi (and a member of the LRG Medical Advisory Board) and connecting with The Max Foundation and Sachin Sarcoma. She also found the Life Raft Group though an internet search when newly diagnosed, became an LRG member a decade ago, and has kept in close contact with our Program Services and Patient Registry Staff throughout her journey. Of the group that she works as City Leader with, she said:

"Friends of Max is an India based support group for CML and GIST patients on lifelong therapy. They are the recognised support group arm of Max Foundation, USA. I am a dedicated volunteer of this organization which empowers the patients by giving them a platform through multiple meetings and seminars, organised by Viji Venkatesh and her team, which enables the patients to share, learn and grow from each others experiences."



"I am a hardcore optimist. I live and appreciate life as it comes. My GIST was diagnosed in November 2007 and prior to that in 2003 I was diagnosed with papillary carcinoma of thyroid. These two cancers have been a great learning experience to me. My family has been my strength throughout this journey and I believe that there is a Power above me guarding and guiding me every moment."

Nandini Dabbir

GIST have access to Ayvakit (avapritinib).

"I think access to medicine has been difficult for many Indians and I think I can play a role in changing that dynamic with the LRG's support," said Nandini.

Through her journey Nandini has remained hopeful with the support of her family and her attitude of positivity. We welcome her to the roster of amazing global representatives of the LRG.

Her journey began with a single tumor and treatment of surgery and Gleevec, but has now progressed to multiple tumors (slow-growing), exons 11 and 17, with a current treatment of Sutent, the second-line treatment for advanced GIST. For now, Nandini is doing well and managing her side effects well enough to pursue her passion of helping others, but is concerned about access to ripretinib, which might be more effective for her in the future, though not available in India. Access to all medications that can treat GIST is a problem for many in the international community and another issue that she is passionate about.

Currently imatinib, sunitinib, and regorafenib are available to patients. Ripretinib, commercially known as Qinlock, can be effective in treating GIST patients who have failed the first three treatment lines but is not currently available to patients in India. Patients who have the PDGFRa D824V mutation in

Friends of Max
<https://friendsofmax.info/>

Sachin Sarcoma Society
<http://www.sachinsarcomasociety.org/>

GIST Awareness Day Is July 13th

#GISTAwarenessDay #TimeToGetTested #ItsTime

GAD TikTok Challenge

Each year we offer up many ways to celebrate and increase awareness about this rare disease on GIST Awareness Day, July 13th. This year we'd like to engage our community to share their stories about biomarker testing and its role in their treatment in conjunction with our It's Time campaign. This campaign has focused on testing all patients in order to insure the most effective treatment possible.



The Challenge: Create a short TikTok or video sharing about how testing has guided you or your loved one's treatment. You can post to your TikTok and tag us @liferaftgroup or you can share a video to social@liferaftgroup.org and we will post that to our social media channels.

Suggested 'script': We encourage you to share your experience in your own words, but if you need a prompt to get started, we suggest: "It's GIST Awareness Day! I'm Jane Smith, exon 17, and biomarker testing helped me get the treatment that has helped me to survive and thrive with GIST. Do you know your mutation? It's Time to Get Tested and Save Lives!"

Hashtags: Please use #GISTAwarenessDay #TimeToGetTested #ItsTime when posting. If you want to share mutational testing resources you can share this link: <https://liferaftgroup.org/timetogettested>

We welcome all submissions and encourage you to raise awareness for GIST anyway you can.

If you are interested in mutational testing and need more information, you can check out the resources link above and/or email our Patient Registry Director, Denisse Montoya, at dmontoya@liferaftgroup.org



Outside my window, Mother Nature is showing off. An explosion of green and flashy colors is everywhere. Bold yellow forsythias dance in the breeze with the heady aroma of lilacs as an undernote. The deep green of the budding trees and the velvety emerald of the lawns are a herald of things to come. After a long winter, there are signs of hope. My Master Gardener friend informs me that the lushness of the plants this spring is due to the amount of snow we had this winter, contributing extra nitrogen to the soil.

It was a difficult winter. This pandemic has affected us as surely as the cold made us shiver, and the icy conditions

forced us to hunker down. It was winter regardless of where we were located, or how much snow we had.

And now, signs of resurrection are all around us. Nature provides the obvious visual, but there are other signs that things are beginning to shift. Vaccinated families are reuniting with their loved ones, Patients are feeling more comfortable going in person for medical appointments. Businesses are starting to reopen. People are going back to work.

The pandemic is not over, and for our patients and caregivers in affected areas of a resurgence of COVID, we continue to offer support to help them navigate their GIST journey. The small miracles we are witnessing, however, promise hope for the future. The science that developed the vaccines enabling us to be together, hug our grandchildren, and get back to a sense of normal, is also the science that continues to hold the promise of new treatment lines and eventually a cure for GIST. Science is the nitrogen that will enrich the soil of future treatments of those with a cancer diagnosis.



Visit our website Events Calendar to register for events and check regularly for new webinars & special events.

In Loving Memory of Ted Wolf



October 2nd, 2021

<https://lifteraftgroup.org/event/gist-do-it-walk-nj-3/>



Join us at 12pm ET for a
Q&A with SDH Experts
featuring a panel of experts from our
Pediatric & SDH-Deficient GIST Consortium

**MONTHLY VIRTUAL GISTer
SUPPORT GROUP**

First Tuesday
of Each Month
6:00 PM - 7:30 PM ET



**VIRTUAL CAREGIVER
SUPPORT GROUP**

1st & 3rd Wednesday
of Each Month
1:00 PM - 2:00 PM ET



JOIN US!

BECOME A MEMBER OF THE LRG
JOIN TO RECEIVE SUPPORT
AND RESOURCES TO ASSIST YOU
ON YOUR GIST JOURNEY!



[HTTPS://LIFERAFTGROUP.ORG/JOIN-OUR-COMMUNITY/](https://lifteraftgroup.org/join-our-community/)

“ **#GIST
HOPE**

I can't thank you enough for everything you and the rest of the Life Raft Group do for patients and caregivers! The level of help, from support groups to educational webinars is second to none. I will never be able to repay you all! HUGE thank you!

- Beth Kroll

”



For more info on how to become a GEM,

visit the [Donate](#) page on our website.

Our major donors: February, March, April & May!

Ameriprise Financial	Claudia & John Link, Inc.
Bank of America	Teena Petersohn
BST Consultants	Palermo-Ravich Family Foundation
Deutsche Bank	Perkins Foundation
Pete Dewalt	RBC Capital Markets, LLC
Fidelity Charitable	Karen Serra
Helen Frey	Wendy Williams
Beth Kroll	
Cathryn Kwart	

Opal

John Driscoll
Linda Gosser
Susan Migneault
Elizabeth Skree

Ruby

Rene Carrillo
Michelle DeValera-Gibson
Sharon Genovese
Janet Hines
Linda Jackson
Jeffrey Jobe
Jean Jolin
Derek Kaufman
Jennifer & Owen Moore
Rick Paczewski
Christa Pereira
Rob Taylor
Daniel Welch

Sapphire

Colleen Carney
Gilbert Tisdale
Alberta Tate
John Van Hise
Danielle Williams

Emerald

Robert Sholiton
Saeed Foudeh

Diamonds

David & Jodi Alexander
Liana Baldor
BST Consultants
Dolores Hawkins
Teena Petersohn

GDOL Sponsors



Biomaker Testing Campaign Sponsors



SPREADHOPE

donate

Help us continue to provide services to GIST patients & fund GIST research.

Donate today
lifteraftgroup.org/donate

Need more info? Contact:
DNieves@lifteraftgroup.org

volunteer

The Life Raft Group needs **translators.**
Read & write fluently in a language other than English?

Contact:
pfernandez@lifteraftgroup.org

connect

Share your story, suggestions, life experience with GIST - give & get encouragement on:

GIST Chat* (a private email community for GIST patients)

GIST Survivor on Facebook (private, moderated by The LRG)

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

*For info, email info@lifteraftgroup.org

The Life Raft Group Global Community

Staff

Executive Director	Norman Scherzer
Senior Vice President	Laura Occhiuzzi
Vice President, Program Services	Sara Rothschild
Senior Director, Research	Pete Knox
Senior Director, Outreach & Engagement	Diana Nieves
Director, Communications	Mary Garland
Director, Marketing & Operations	Matthew Mattioli
Director, Patient Registry	Denisse Montoya
Director, Outreach & Engagement	Jessica Nowak
Administrative Director	Allison Russo
Assistant Director, Communications	Carolyn Tordella
Patient Registry Supervisor	Sahibjeet Kaur
Data Analyst	Jerry Call
Data Analyst/Patient Registry Associate	Maeven Luedke
Operations Manager	Helena Mattioli
Web Associate	Eddie Delgado
Fiscal Director	Robin Elia
Patient Registry Associate	Jordanne Nelson
Patient Registry Associate	Antoinette Pauwels
Consultants	
Global Relations Coordinator	Piga Fernández
Grants Consultant	Elyse Reissman

Interested in Volunteering?
Contact: Diana Nieves, Senior
Director, Outreach & Engagement
dnieves@liferaftgroup.org

Volunteers

Pediatric GIST	Erin MacBean
Official Greeter	Gail Mansfield
Clinical Trials Coordinator	Jim Hughes
Staff Photographer	Michelle Mattioli
General Counsel	Steven Pontell
Science Team	Erin MacBean
	David Josephy
	Michael Josephy
	Joan Krakowsky
	Jim Hughes
U.S. GIST Mentor Director	Santy DiSabatino
U.S. GIST Mentors	
Eric Biegansky	Karen Meyers
Bettina Darveaux	Marlene Nei
Jason DeLorenzo	Carolina Ponce
Carolyn Dewalt	Kay Stolzer
Julie Durkee	Pat Bonda Swenson
Saeed Foudeh	Rob Taylor
Diana Garrett	Marc Wasserman
Chuck Korte	
Global GIST Mentor Director	Piga Fernández
Global GIST Mentors	
Austria	Amy Bruno-Lindner
Canada	Hazel McLeod
Chile	Piga Fernández
India	Rashmi Sachade
	Satheesh Kumar Sreedharan
	Sreeja Jyothish
Singapore	Amelia Yeo

Board of Directors

Executive Committee
Jerry Cudzil – President
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)
Kay Stolzer
Dr. Monica Anderson
Medical Advisory Board
Dr. Michael C. Heinrich
Dr. Sameer Rastogi
Dr. Peter Reichardt
Dr. Gary Schwartz
Dr. Jason Sicklick
Dr. Jonathan Trent

**Interested in serving on
the LRG Board of Directors?**
Contact: Laura Occhiuzzi,
Senior VP
locchiuzzi@liferaftgroup.org

U.S. State Representatives

Alabama	Kyle Brown	Maryland	Wendi Lax	South Dakota	Paul Homan
	Gina Smith	Michigan	Ellen Rosenthal	Utah	Mike Ginsberg
California, Southern	Dina Wiley	Minnesota	Ananth Pai		Carrie Callister
Colorado	John Abrams	New York	Pat Bonda-Swenson	Vermont	Elizabeth Ching
Hawaii	Erin Rakes		Frances Wenderoth	Virginia	Sally Jackson
Illinois	Jim Hughes	North Carolina	Jennifer Higgins	Washington	Jack Tinnea
	Marlene Nei		Carolyn Dewalt	Wyoming	Alan Quille
Kansas	Christine Engel	Pennsylvania	Tiffany Werner		
Maine	Jodi Merry	South Carolina	Paula Stover	Puerto Rico	Eileen Rolon

Global Representatives See global news & resources in our International section on our website.

Australia	Shari Reid	Hong Kong	Thomas Chow	Phillipines	Roy Mijares
	Amy Kenworthy	Hungary	Zoltan Kalo		Ron Padua
Austria	Amy Bruno-Lindner		Andras Szekfu	Poland	Piotr Fonrobert
Belgium	Gerard van Oortmerssen	India	Nandini Dabbir	Romania	Simona Ene
Bolivia	Vicky Ossio		Rashi Kapoor	Russia	Dmitry Bukhtenkov
Brazil	Luciana Holtz	Iran	Negar Amirfarhad	Samoa	Leasi John Galuvao
Bulgaria	Juliana Popova	Israel	Avi Zigdon	Saudi Arabi	Mohamed-Elbagir Ahmed
Canada	David Josephy	Italy	Barbara Tamagni Colombo	Scotland	Stacey McAully
Chile	Piga Fernández	Japan	Sumito Nishidate	Singapore	Amelia Yeo
Colombia	Adriana Garzón Pinzón	Jordan	Sameer Yaser	South Korea	Young Jae Kim
	Jairo Beccera	Kenya	Florence Thwagi	Spain	Luis Herrero de la Fuente
Costa Rica	Michael Josephy	Macedonia	Dejan Krstevski	Sudan	Mohamed-Elbagir Ahmed
Cyprus	George Constantinou	Mexico	Rodrigo Salas	Switzerland	Helga Schnorf
Czech Republic	Jana Pelouchová	Nepal	Atul Upadhyay	Thailand	Kittikhun Pornpakakul
Dominican Republic	Alejandro Miranda	Netherlands	Gerard van Oortmerssen	Tunisia	Hanen Bouamoud
Finland	Saila Mattila	New Zealand	Joy Rycroft	Turkey	Haver Tanbay
France	Estelle LeCointe-Artzner	Norway	Frode Homb	Ukraine	Larisa Kutovenko
Germany	Markus Wartenberg	Pakistan	Sobia Wali Muhammad	U.K.	Jayne Bressington
Greece	George Constantinou	Peru	Karla Ruiz de Castilla	Uruguay	Verónica Armand Ugón
Guatemala	Silvia Castillo de Armas			Venezuela	Angel Selena Rodriguez

155 US Highway 46, Suite 202
Wayne, NJ 07470
phone: 973-837-9092
fax: 973-837-9095
email: liferaft@liferaftgroup.org
website: www.liferaftgroup.org



Facebook - facebook.com/liferaftgroup
Twitter - @Liferaftgroup
LinkedIn - linkedin.com/company/the-life-raft-group
YouTube - youtube.com/LifeRaftGroup
Instagram - instagram.com/liferaftgroup