

Ensuring no one has to face GIST alone



In Loving Memory: Adam Sangillo, Susan Leah Williams



A Positive Spin for 2022

Jimit Mody's GIST Journey

By Carolyn Tordella, Assistant Director of Communications

Let's be frank. 2020 and 2021 were not most people's idea of a normal year. Being positive, reframing our expectations, and creating self-care techniques for coping may be things that you're had to cling to in order to make it through these difficult times. What is the value of a positive attitude? Does having a positive attitude bring a positive result when it comes to cancer? Here's one patient's story that may help you see what a positive attitude/lifestyle can bring to the table when thriving with GIST. Jimit Mody was 24 years old when he came face-to-face with cancer.

Jimit's story continues on page 4

There's still time to give



Donate today





Thoughts from our Executive Director

Sam Middleton died today at age 38. He leaves behind a wife, three children and next year's calendar full of simple wishes. They include four birthdays, two ballet recitals, one graduation, a family trip to Disneyland, grandma and grandpa's 60th anniversary and painting the family room. His chair sits unoccupied at the dinner table and his side of the bed remains empty when his wife reaches out at three in the morning as she has done for 18 years. The death certificate is brief and reads "organ failure due to gastrointestinal stromal tumor." Locked in his physician's file cabinet is his medical record which failed to show that he had not been given the right diagnostic test that might have pointed to that new effective targeted medication. His official pharmaceutical record reads that he achieved "4.7 years of overall survival."

A man named Sam Middleton did not actually die today. He is a fictitious character created from a composite of cases stored in The Life Raft Group data base. But Sam represents the reality of those whose lives have been unnecessarily cut short despite the availability of a targeted treatment. Equally important, he represents the reality of unfulfilled patient wishes as they struggle with cancer.

Perhaps we need to change the measurement of cancer treatment progress from a number representing survival time to a compendium of gifts of time both for those we have lost and those who carry on.

When my Anita was first diagnosed with what turned out to be GIST and given six months to live, I created a survival plan. At the top of the list was to always have something to look forward to A trip as soon as she recovered from surgery. A new outfit as soon as her CT Scan ended. And so on. Anita survived 23 years with GIST only to succumb to an infection.

I, too, need a wish to always look forward to as the Life Raft Group plods on, sometimes with great success and fanfare and sometimes with silent gritting of teeth as we crawl over another hill to bring hope to a child in distress or a grandparent in pain.

Help us make those future wishes come true.

We have many family dinners to share and playground swings to push.

- Norman J. Scherzer



The Life Raft Group 2021 Holiday Campaign - #GISTWish List

As we enter the holiday season, our thoughts turn to the new year to come. We've made a list of our holiday wishes:

- ▶ No patient dies because they didn't receive the correct diagnosis or effective treatment.
- ▶ To close the lethal time gap between breakthroughs in research and treatments and the ability to access them.
- ▶ To find effective treatments for the rare subsets of GIST, especially for pediatric patients.
- ▶ To make genomic testing the standard of care for all GIST patients early in their treatment journey.
- ▶ To continue providing education for patients and caregivers through our website, webinars, and GIST Days of Learning.
- ▶ To continue providing support for patients and caregivers through our GIST Mentor programs, support groups, and our biennial Life Fest.
- ▶ To work with collaborators such as our Pediatric & SDH-Deficient GIST Consortium and the LRG Global Surveillance Team, supporting research initiatives.
- ▶ To find a cure.

Help us make these holiday wishes come true!

It won't happen by waving a wand or rubbing a bottle to summon a genie but by the generous donations from people like you. Donate today or create a crowdfunding page of your own!



Donate: <https://bit.ly/lrgdonate21>

Continued from cover

Jimit Mody



Born and raised in India, Jimit was living with his family in Maharashtra, India, in 2016 when he began experiencing a constant, sharp pinching pain in his abdomen.

It wasn't unfamiliar to him - he'd had an episode of like this once in 2015 but after blood tests and an ultrasound the result was that he was prescribed medicine for acid reflux. This issue was considered cured, and was forgotten, until the same pain recurred a few months later.

Jimit had been busy making plans to come to the United States to study for his master's degree at SUNY Binghamton in New York State. These plans were put on hold because this episode caused Jimit's doctor much more concern and tests were ordered to investigate further. A CAT scan revealed four large masses. Jimit's doctor and radiologist told him there were three possibilities -

- 1) it could be something malignant,
- 2) it could be something benign, or
- 3) it could be tuboglossis tuberculosis.

A fine needle biopsy was scheduled, and the tumor sample was sent to a special lab in the capital city of Mumbai.

With test results that showed a GIST diagnosis, positive for C-KIT but negative for any other mutation, Jimit was referred to a medical oncologist in Mumbai who reassured him that it wasn't an aggressive type of cancer and that there were treatments available. Neoadjuvant imatinib was prescribed and scans would be done six weeks later.

Faced with this new reality, Jimit decided to ask for and was granted deferred admission to his master's program.

Jimit's reaction to this all this might be typical, but his determination to move forward is noteworthy. "It was a big shock, a terror. I was down at first, but acceptance came in. I thought 'this is a speed bump and I'll get over it.' There are many more important things to do. I will take care of this but I will get on with it [life]."

Jimit and his brother (and a few family members) dove into the internet to do research on GIST as well as getting a consult from a family member who is a gastrointestinal surgeon.

"My older brother and I are very inquisitive by nature, so we started Googling stuff and reading articles in various scientific journals and

we understood that since I was just KIT positive and negative for all else, it means wildtype, as per the pathology, so we questioned continuing the imatinib, but it is considered the first line of treatment," said Jimit.

Jimit's family rallied with everyone lending their support researching this disease and talking to people about it.

At six weeks, scans showed a 5-10% reduction in the tumors, but by the next scan there were no more positive changes, and one of the tumors showed signs of growth. Surgery was performed in September 2016, and it was complex - a partial gastrectomy, splenectomy, gastrojejunostomy, and a debulking of the peritoneum.

"I don't hold my cancer story back. People ask me about the white hair. I'm not shy about sharing my story, I want to help others. I like to be upfront."

Story continues on next page

"I began imatinib again about a month after the surgery. I was recovering well. After surgery, I met with a naturopathic practitioner, who was a yoga teacher who also helped me develop a customized diet based on my body type, my blood group, what my tendencies are, and what my history is. And he worked with me to detox and clean up my entire system after the surgery," said Jimit.

In January 2017, Jimit had his first post-surgery scans, and they were clear. Though Jimit had a new nutritional regime and his body was healing well with yoga, enriched by positive affirmations and exercise, he searched for answers to the real questions about GIST.

"The scans after surgery were clear, NED, and that was good, but at the same time, we wanted to get to the root cause of the disease. And as you know we don't know the root cause of GIST. I continued the naturopathic practice and added ayurvedic practices¹ and Tibetan medicine², a 2000 plus year-old science. They do urine and pulse analysis and give you natural herbal medicines. We were trying to prevent it from coming back. These practitioners did not believe these methods would interfere with the traditional medicine," Jimit shared.

In conjunction with Jimit's desire to know more about GIST and what might be next, his oncologist sent tissue samples to the United States to several labs for a second opinion on the pathology of his tumors. One confirmed the Mumbai lab's findings and another gave him more information - he had SDHB-deficient GIST. His local oncologist felt Jimit should continue imatinib since he's had few side effects and his scans were still clear. That doctor also felt that Jimit was ok to continue all the alternative therapies he'd been doing.

Jimit was still doing well in April of 2017, and made the decision to leave his job and backpack across northern India with some friends. He commented on this decision:

"It was part of the country I'd never visited before. Mountains, waterfalls and lakes. I was with a couple of good friends. I wasn't sure I'd be able to do any of the trekking since I had just had major surgery, but I did well. I think the diet and the yoga, and my age helped. I just needed some 'me time'."

After his travels, Jimit began to make preparations to travel to the United States in August to begin his studies at SUNY. He was nervous about leaving his family and moving to a new country and living with GIST on his own, and though his family was sad to see him go, they were very supportive. Everyone felt reassured when Jimit's last scan before he departed was also NED.



Story continues on page 6

Story continued from page 5

The semester at SUNY was a blur of learning new things, getting used to a new country, making friends, keeping up with studies, part-time work, and continuing his routine of nutrition, exercise, and mental health practices that Jimit knew worked for him living with GIST. By the end of the semester, Jimit was quite homesick and he made plans to travel home for the holiday break. While he was at home, he got his scheduled scan and unfortunately it showed multiple spots of activity. An MRI and PET scan confirmed that it was a recurrence as well as several metastases in the abdomen and the liver. His local oncologist discontinued the imatinib due to the new growth and recommended that since he was living in the US he should explore what doctors in the United States were doing as far as research and clinical trials in SDH-deficient GIST. And explore he did. Jimit's case was evaluated by doctors in Boston and New York City, with, and eventually, in the search for answers, Jimit spoke with doctors in Portland, California, Florida, and even Germany.

Jimit's oncologist prescribed Sutent which he took without too many side effects until a few months later, but they were tolerable. A consultation with Jimit's natural and alternative medicine practitioners led to some changes, and scans and bloodwork continued regularly. In his quest to find more information on SDH, Jimit attended the Pediatric & Wildtype Clinic sponsored by the NIH in 2018 in Washington, D.C. At this event, he met and bonded with several other young adults who were dealing

with life with SDH, and this is where he met Sara Rothschild, Senior Vice President of Program Services for the The Life Raft Group as well.

"When I was at the NIH, I saw that I had nothing to complain about. I saw teenagers who were just handling it," commented Jimit. Jimit found a rich source of information, comradery and support from the staff, fellow patients, and advocates at the Clinic.

Now settled in Pittsburgh in a new job, Jimit remains stable at this point and stays in touch with his new friends and in addition to many practitioners across the country who are keeping abreast of his case and who he relies on for their expertise.

Jimit shared that he's learned a lot about himself since his diagnosis.

"It's revealed a few traits of mine that I didn't know that I had. The mental strength to not get bogged down by the negative. It's made me look at the positive side of everything and be more optimistic about life. I don't wish to toot my own horn, but I've been able to be very disciplined with my diet and lifestyle, working as a student, and balancing that with my studies with decent grades. Nothing is impossible. And at the same time it made me realize that I don't have to take life so seriously all the time. I have learned to also live in the moment. To talk to more people, say my positive affirmations, not be scared of challenges, learn to pick myself up, look forward and to find solutions. These are things that I had to learn because I had to deal with life and death so young."



Story continues on next page

Story continued from page 6

Jimit also says that for those newly diagnosed, they need to understand that, "Being afraid is not wrong. We're all human. But keep a positive mindset - I have this, I accept it and now let's move on, what can we do now? Be happy and be free. Convince your body that you're fine.

I take a positive approach to everything. If I had stayed down because of my illness, my parents' death, financial issues, it would have slayed me. Don't give up, just go for it. Keep a mindset that you're going to beat it."

A normal reaction to a cancer diagnosis and cancer treatments is depression and sadness and though positivity will not cure you, when you are ready to adapt one, a positive mindset can help you manage your adherence to a self-care routine and enhance your mental health as you live with GIST. If you are new to a cancer diagnosis, or caretaking, or are at any point in your GIST journey, please know that there are many resources available to support you in any way you need.

The Life Raft Group offers virtual support groups for patients and a separate gathering for caregivers available to all. Across the country patient and caregiver groups meet with LRG State liaisons at in-person support meetings (depending on current covid restrictions).

We also have a **GIST Mentor Program** (<https://liferaftgroup.org/lrg-gist-mentor/>) where patients are matched with patients with similarities (age, mutation, etc.), and caregivers with other caregivers for support and encouragement one-on-one. Online, LRG Members can access GIST Chat, a private, email community with patients and caregivers who discuss everything under the sun that a GISTer may encounter. Across Facebook there are several private groups for GIST: **GIST Survivor** (<https://www.facebook.com/groups/43875181964>) is moderated by The Life Raft Group is a forum for more than 1000 patients/caregivers. There are also many regional groups of GISTers as well for Australian, Asian, and Latin America.

As for information, be sure to visit our **website** (<https://liferaftgroup.org/>) where research, mutation information, upcoming events and handy charts for the newly diagnosed are accessible. You can also find dozens of videos on all aspects of GIST on **our YouTube page** (<https://www.youtube.com/channel/UC2gRE7t-kZkgH02Taibe7IQ>). If you need to speak with someone about your pathology test, finding a GIST expert, or about getting mutational testing, please email liferaft@liferaftgroup.org or call 973-837-9092.



References:

¹ **Ayurveda** - Ayurveda, or ayurvedic medicine, is a healthy-lifestyle system that people in India have used for more than 5,000 years. Ayurveda emphasizes good health and prevention and treatment of illness through lifestyle practices (such as massage, meditation, yoga, and dietary changes) and the use of herbal remedies. Ayurvedic theory states that all areas of life impact one's health, so it follows that the Vedas cover a wide variety of topics, including health and healthcare techniques, astrology, spirituality, government and politics, art, and human behavior. University of Michigan, <https://www.takingcharge.csh.umn.edu/where-ayurveda-come-from/>

² **Tibetan medicine** - Tibetan medicine teaches that the purpose of life is to be happy. By using Tibetan medicine for self-care, you will become aware of how your thoughts and behaviors influence your health and happiness. University of Michigan, <https://www.takingcharge.csh.umn.edu/philosophy-tibetan-medicine/>

As always, please consult your GIST expert before making any changes to your diet, nutrition, exercise routine, or lifestyle. This information is not a substitute for their expertise.



An Exceptional Volunteer & Friend of the LRG



Chelsea Madia

By Diana Nieves, Senior Director, Outreach & Engagement

Chelsea (Ozeri) Madia, LCSW, was referred to us in February 2019 by Karen Kelley who is a former staff member and longtime friend of the LRG. I remember welcoming Chelsea to the LRG and at that time I knew Chelsea would be a quiet storm within our community. It was during our first call she noted that she wanted to volunteer and give back to the LRG. Within a few months, Chelsea became our **LRG patient of the month in May 2019*** because of how much she advocated for her own care and she became an immediate overall positive influence in many GISTers' lives. Since her diagnosis, she began viewing life differently and started eating healthier, meditating/exercising more regularly, and choose to live more consciously with what she wanted to do with each day of her life. Chelsea's advice was to simply live more intentionally and that she has been doing every day.

It was also in May of 2019 that Chelsea received the Wolf Strong Award during LRG's first GIST Do It Walk New Jersey for increasing awareness about GIST in New York, advocating for her own and others' care, and raising over \$10K towards GIST research. It was during that walk that Chelsea met others and continued to be a strong voice within the LRG community. Her voice and presence at the GIST Do It Walk were just the beginning demonstration of this GISTers fortitude and philanthropy.

Chelsea's volunteer endeavors didn't stop there. In April of 2020 when the COVID pandemic was in full swing, Chelsea reached out to me and asked if she could do more utilizing her professional expertise as a licensed social worker, GIST wisdom and overall approach to living life more consciously. It was then that we decided to offer the LRG community a weekly support group to GISTers to which Chelsea would lead for the next year and a half. This was a tough time for so many and especially GISTers who were facing fears about COVID and being unable to see their doctors for scans, treatments, and surgeries due to COVID patients spikes in hospitals. Chelsea naturally gives with her whole heart and in any way that she can to people who need it. She is a smart and funny facilitator and an overall great human being.

*Thank you so much, Chelsea,
for all that you have done for the LRG,
& our community of GISTers & loved ones over the years!
There are no words to truly describe our gratitude.*

* <https://liferaftgroup.org/2019/05/patient-of-the-month-chelsea-ozeri/>

“Being part of a support group for me has helped me tremendously, not only did I get to connect with others that have my type of cancer I was able to express how I am feeling during all of this. This group has helped me come out of my shell as I am not a person who normally talks about my feelings. This group I made more of a connection with names and faces. Having a support group of people who may not be going through the same thing as you per se, they still understand and give you advice when asked. There are many intelligent people as well as those who are just starting this journey but each of us completely understand what someone maybe feeling or just helping them understand what is happening. This group had a variety of people, walks of life, and different stages of Chemo which helped because you can just be there to listen. Thank you for offering this to our community. I loved the fact that I made more friends who are like me and understand the GIST of things lol.”

- Michele

“I could describe my feedback in one word: FANTASTIC. This was a highly emotional group, sharing your experiences with others with the same challenges was quite an experience.

The meetings turned out to be very constructive focusing on support of each other instead of personal issues. I felt sense of connection to others and enjoyed interaction with fellow GISTers. Chelsea, you are awesome and did an outstanding job leading the group.”

- Saeed

“The LRG Emotional Support Group has been a terrific support to me. The facilitator, Chelsea, is fantastic -- very professional and very sensitive to our issues and needs to speak and refrain from being critical or criticized. Only good ideas have been generated for me by my participation.” - Aliza

“Thank you, so much, for allowing me to sit in with today's group. The participants were so open in discussing their feelings and emotions. It was obvious everyone knows they are in a safe environment, comfortable, as well as supported by all. The camaraderie amongst everyone was heartwarming.”

- Marlene

“Having cancer can be such a lonely battle as no one can really know what you are going through emotionally, mentally, and physically except for those who are on the same path as yourself. Having the friendship, kindness, support from other GISTers who understand firsthand what you are going through is just so special. Battling cancer is a struggle and having this special group wrapped around you like a blanket provides so much comfort, warmth, and the realization that indeed you are never alone. Hearing other members stories and what they endure is so inspiring and gives me the strength and courage to get through those bad times. The urge to help others is an important focus, as we all want to do what we can to help alleviate each other's pain and suffering. We are all in this together and that makes us so much stronger.”-Bettina



“I've been in other cancer support groups; however, all types of cancers were represented. While that has been helpful, it is more general to the challenges that all cancer survivors face. I find this group especially helpful, as a 2nd lesion was found in my recent MRI. Others in the group had experiences with the different medications my oncologist has been recommending, so I don't feel like I'm going in blind, like when I started with Gleevec. It helps me to make a more informed decision about what my options are. Our facilitator poses a question for each session mainly based on how we navigate through this healing journey of cancer. I get to try different ways of self-care that I hadn't thought of. And, I also find that many of us are quite creative and resilient in ways we find to self-care.” -

Gayook

#GIST Wishes & Wishes Fulfilled

By our LRG GIST Community

In addition the #GIST Wishes we made for our holiday campaign, we wanted to share some from our LRG Community. You can read about our campaign at <https://liferaftgroup.org/2021/11/holiday-campaign-lrg-wishes-2021/>.

To develop new and better treatments for the rare GIST subtypes, including SDH-deficient GIST.

- Dr. Jason K. Sicklick, California, USA

That patients find their way to a dedicated GIST expert to receive best possible treatment and care.

- Dr. Peter Reichardt, Germany

To recruit patients all over the world for clinical trials

To end disparity at the various level in the management of GIST

To unite people all over the world for better advocacy

To make and update guidelines for the management of GIST

To identify the role of off label therapies like cabozantinib and pazopanib in GIST

- Dr. Sameer Rastogi, India

"I have been able to see my daughter and sons become adults and meet my grandchildren"

- Piga Fernández, Chile

The wish that I feel blessed to say has been fulfilled this year has been to say that the many GIST mentees I have had the privilege to connect with are all still with us and doing relatively well from a health standpoint. It has been tremendously gratifying to get the good news about a stable scan or to hear my mentees confidently share a path forward, enabled by being connected to the right medical GIST specialists. We all know that dealing with GIST is very challenging on a physical, psychological and emotional level; this is why we must continue to celebrate those who continue to fight and never lose hope. In the words of Winston Churchill: "when you're going through Hell...keep going!"

- Eric Biegansky, GIST Mentor & Board member, Illinois, USA

I have been able to continue studying medicine and help others to thank all for the support I have received.

- Angel Rodriguez, Venezuela

When I was diagnosed I wasn't sure if I would ever hike with my Boy Scout troop in Philmont. Not only did I do that, but over the summer I achieved my Eagle Scout and also graduated high school."

- Bryce Werner, Pennsylvania, USA

"When I was diagnosed with GIST at 18, my hope was to reach my 21st birthday. That was the first wish and milestone I dreamed of reaching. As I reached my 21st birthday I set my next wish - "Get married one day" . I feel very fortunate to be living with GIST for 25 years of joy, laughter and a long list personal milestones. My most significant is being married for nearly 20 years and having an amazing son. My hope and dream is to see him graduate from high school in 3 years time.

Living with GIST is hard and relentless, but dare to dream and make a wish. Fill your mind with hope, because you never know, your wish just might come true. I had moments at 18 years old thinking my adult life was ending just as it was about to begin. I held onto the hope that medical research would guide me through. That hope has carried me through and I'm still here. I'm a 42 years old primary school teacher with an amazing husband and a fabulous son. My hope and dream is to see him graduate from high school. I have found strength on the tough days hanging onto hope and keeping my head up looking at the horizon. It has been a winning formula for me for 25 years, and I'm not done living yet. Make a wish and Happy Holidays. "

- Sarah McGoram, Australia

One of the deepest wishes in my heart, was to see my girl grow. When I was diagnosed, I thought that it would be impossible, she only had 2 months; but today, my daughter has 10 months and I have seen her grow healthy and strong. Until now, this has been my greatest wish and it has come true.

I wholeheartedly desire that each one of the wishes of GIST patients could come true and that we can have an excellent Christmas.

I wish that every GIST patient could have a good emotional health and never lose hope in front of any diagnosis that might be dark or negative. I wish that all GIST patients could have on time access to their treatments and that all of them could go to their medical checkups. Let's live every day as if it were the last one, with intensity, passion, not focusing on what we are missing, but on what we now have, so that seeking the perfect won't prevent us from enjoying what we have in front of us. Happy Christmas!

- Alberto Rodríguez, Venezuela

My nephew and his wife had been trying to get pregnant for several years. In April they finally announced that they were pregnant and due with twin boys in December. After over a year of my industry being completely shut down, we finally had our first trade show in August.

- Pat Bonda-Swenson, New York, USA

My wish when I was diagnosed with GIST was to hold my first grandchild. I am grateful to God for my grandkids, Natasha who is 3 years and Eliam who is 1 year old. I trust and believe that I will live to see my Great Grandchildren!

- Florence Thwagi, Kenya,

My wishes for 2021 included being grateful to have another year that I could spend with family, friends and fellow gist mentors, and people I mentor. I appreciate all The Life Raft Group does day in and day out to support the mentoring program and all people with GIST and their caregivers.

- Santy Disabatino, GIST Mentor, South Carolina, USA

Two examples of mentee caregivers whose wishes have been fulfilled this year:



I was 27 weeks pregnant when my GIST was confirmed, and hearing that diagnosis was terrifying. I was afraid I was going to miss out on watching my daughters grow up. It's been a year and a half since then, and so far I've been able to experience everything with them! Trips to the zoo, family time at the pool, going on road trips, hearing my youngest say her first word and watching her take her first steps!

- April Lopossa, Indiana, USA

1) My mentee's son was not doing well since his GIST diagnosis. Her son did not use a GIST specialist because he was happy with his local oncologist. I suggested my mentee register for an upcoming LRG webcast to listen to Dr. Trent. After hearing him, she and her son had a consultation with Dr. Trent. They now continue to have regular televisits with him, keeping their local oncologist as part of their team. Since under the care of Dr. Trent, her son has been NED and doing very well.

2) Another caregiver mentee whose husband is the GISTer, being treated by a local doctor, spent the past 3 years since her child was born, trying to find answers for the medical issue the child was born with. After working with LRG, she has been referred to a pediatric GIST specialist for her son, and her husband is being referred to a GIST specialist.

Both of my mentees' wishes are being fulfilled with the help of LRG's efforts.

- Marlene Nei, GIST Mentor, Wisconsin, USA

Clinical Trials Update

By LRG Staff



In this summary, we have highlighted recent clinical trials that are still recruiting in the U.S. which investigate potential treatments for GIST patients. Our database, gisttrials.org, lists over 70 trials that are GIST-related which are ongoing around the world. Currently there are 11 GIST-related trials recruiting in the United States. (Of these 11, two are no Phase (0), three are Phase 1, five are Phase 2, one is Phase 1/2.) This article gives a sampling of four trials currently recruiting for KIT/PDGFRa mutant GIST, SDH-deficient GIST (2), and a no Phase Surgery trial for all GIST Types.

For further information about GIST trials including international trials, visit:

The Life Raft Group Clinical Trials Website: <https://gisttrials.org/>

About Phase 1 trials: It is important to recognize that Phase I studies are held to find the highest dose of the new treatment that can be given safely without causing severe side effects.

- The first few people in the study get a very low dose of the treatment and are watched very closely. If there are only minor side effects, the next few participants get a higher dose. This process continues until doctors find a dose that's most likely to be an effective treatment while having an acceptable level of side effects.
- Safety is the main concern. The research team monitors participants and watches for severe side effects. Due to the small numbers of people in Phase I studies, rare side effects may not be seen until later phases of the trial when more people are receiving the treatment.
- While some people may benefit from being on one, disease response is not the main purpose of a Phase I trial.

Phase I trials carry the most potential risk, but these studies do help some patients. For those with life-threatening illnesses, weighing the potential risks and benefits carefully is key. Sometimes people choose to join Phase I trials when all other treatment options have already been tried.

For patients with advanced KIT/PDGFRa mutant GIST:

NB003 Phase 1 - "A Study of NB003 in Patients With Advanced Malignancies"

<https://gisttrials.org/iLRG/details.php?Trial=377> Site is Memorial Sloan Kettering Cancer Center NY, NY. Principal Investigator: Dr. Ping Chi. The trial started 8/6/2021. Dose escalation phase will be followed by an expansion phase. Plans are to recruit 36 over a period of 20 months. NB003 oral tablets are administered twice daily for repeated 28-day cycles.

Primary objectives are incidence of dose limiting toxicity and incidence of adverse events. Tumor sample collection is required. Includes GIST and other solid tumors with either KIT or PDGFRa mutations. Includes patients with advanced GIST who have progressed on or had an intolerance to imatinib and other standard of care (SoCs) or refused other SoCs.

Sponsor is Ningbo Newbay Technology Development Co., Ltd in China. Obtained development rights from AstraZeneca in 2020. NB003 was previously called AZD3229. AstraZeneca employee authors described AZD3229 translational relevance in a 2019 paper: "AZD3229 has potential as a best-in-class treatment for patients with GIST with mutations in KIT and PDGFRa, and this compound may overcome the limitations experienced with existing treatment options in the clinic which are limited by off-target effects leading to drug holidays and dose reductions leading to lack of optimum efficacy." Contact at MSKCC, 646-888-3915 or email dastasj@mskcc.org [NCT04936178](https://clinicaltrials.gov/ct2/show/study/NCT04936178)

Story continues on next page

Story continued from page 12

For patients with SDH-deficient GIST

Temozolomide Phase 2 - "Temozolomide (TMZ) In Advanced Succinate Dehydrogenase (SDH) Mutant/Deficient Gastrointestinal Stromal Tumor (GIST)".

<https://gisttrials.org/iLRG/details.php?Trial=354>

Trial sites include University of California San Diego, University of Miami, Oregon Health Science University, Portland, Fox Chase Cancer Center, Philadelphia. Principal Investigators include Adam Burgoyne, Jon Trent, Mike Heinrich, Margaret von Mehren. Started 9/12/2018.

Recruiting 23 participants over 48 months. Temozolomide (Temodar®) tablets taken orally once a day for 21 days followed by seven days off drug for each 28-day drug cycle.

Primary objective is overall response rate. Patients will continue treatment until disease progression or unacceptable toxicity. Includes patients who have pathologically confirmed SDH-mutant/deficient GIST and tumors measurable on CT scans.

Information concerning the rationale for use of Temozolomide in SDH-deficient GIST can be found in the following reports:

- 1/7/2019 - *"Preferential MGMT methylation could predispose a subset of KIT/PDGFR-*WT* GISTs, including SDH-deficient ones, to respond to alkylating agents"*

<https://pubmed.ncbi.nlm.nih.gov/30616628/>

- 10/12/2020 - *"Abnormal MGMT Promoter Methylation in Gastrointestinal Stromal Tumors: Genetic Susceptibility and Association with Clinical Outcome"*

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7568426/>

Information concerning side effects of TMZ in GIST patients can be found in the following report:

- 12/4/2003 - *"A two-arm phase II study of temozolomide in patients with advanced gastrointestinal stromal tumors and other soft tissue sarcomas"*.

<https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.11875>

Sponsor is Dr. Adam Burgoyne. Contact at UCSD at 858-822-3092 or email aburgoyne@ucsd.edu
NCT03556384

Rogaratinib Phase 2 - "Testing the Anti-cancer Drug, Rogaratinib (BAY 1163877), for Treatment of Advanced Sarcoma With Alteration in Fibroblast Growth Factor Receptor (FGFR 1-4), and in Patients With SDH-deficient Gastrointestinal Stromal Tumor (GIST)"

<https://gisttrials.org/iLRG/details.php?Trial=375>

Trial sites include: Dana-Farber Boston, Boston, The National Cancer Institute Bethesda, City of Hope Duarte, CA, Memorial Sloan Kettering New York, NY, Washington University School of Medicine St. Louis, University of Pittsburgh Cancer Institute.

Principal Investigators include: Suzanne George, A. P. Chen, Mark Agulnik, Katherine Thornton, Brian Van Tine, Melissa Burgess. Started 2/1/2021.

Recruiting 48 participants over 24 months. Patients take Rogaratinib pills twice daily on days 1-28. Treatment repeats every 28 days for up to 24 cycles in the absence of disease progression or unacceptable toxicity.

Primary objective is to estimate the objective radiographic response rate. Serial biopsies may be required. Confirmed SDH-deficient patients must have measurable disease on scans. The sponsor is the National Cancer Institute.

The rationale for targeting FGFR in SDH-deficient GIST is provided in the following paper:

- 10/16/2019 - *"Altered chromosomal topology drives oncogenic programs in SDH-deficient GISTs"*

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6913936/>

Information about the safety and side effects of Rogaratenib is provided in the following paper reporting results of a Phase 1 dose escalation study:

- 8/9/2019 - *"Rogaratinib in patients with advanced cancers selected by FGFR mRNA expression: a phase 1 dose-escalation and dose-expansion study."*

<https://pubmed.ncbi.nlm.nih.gov/31405822/>

Contact information is available for each site at clinicaltrials.gov **NCT04595747**

Story continues on page 14

Story continued from page 13

For all GIST patients:

Surgery, No Phase - "Surgery in Gastrointestinal Stromal Tumors (GISTs) for Treatment, Tumor Modeling, and Genomic Analysis"

<https://gisttrials.org/iLRG/details.php?Trial=376>

National Institute of Health Clinical Center in Bethesda, MD.

Principal Investigator is Dr. Andrew M Blakely. Started 12/18/2020. Recruiting 400 participants over 20 years. Participants will be monitored every 6-12 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 6-12 months, for up to five years after surgery.

If a participant has 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.

The overall objective is to follow people with GISTs and collect tumor tissue so that it can be studied in the lab. The Primary objective is to evaluate and follow patients with GISTs, particularly WT or treatment-refractory non-WT, to support translational research for this rare disease Time Frame: on-going. People aged six and older who have GIST are eligible.

Inclusion criteria include: Histological confirmation or clinical presentation suspicious of GIST; histological confirmation will be preferably by review of archival tissue if available, fresh biopsy will not be required if inadequate tissue sample.

Sponsor is the National Cancer Institute. Contact: Audra A Satterwhite, R.N. at 240-858-3552 or email audra.satterwhite@nih.gov **NCT04557969**

This trial is further described on the LRG website:

<https://liferaftgroup.org/2021/06/its-time-11-rare-subsets-clinical-trials/>

Please discuss these trials with your GIST expert to determine which, if any, are appropriate for you.

For more information on clinical trial phases:

<https://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials/what-you-need-to-know/phases-of-clinical-trials.html> & this video [What GISTers Need to Know About Clinical Trials.](#)

(<https://liferaftgroup.org/2021/08/what-gisters-need-to-know-about-clinical-trials/>)

Contact the LRG for more information on GIST clinical trials: liferaft@liferaftgroup.org

GABRIEL L. PLAA, AWARD OF
DISTINCTION



David Josephy, PhD
Retired Professor at Department of
Biochemistry & Molecular Biology
University of Guelph, Guelph, Ontario

Congratulations to David Josephy,
Director of GIST Sarcoma Life Raft
Group Canada! He received the
Society of Toxicology of Canada
Gabriel L. PLAA
Award of Distinction.

*Well deserved,
David!*



LRG Staff Presenting Around the World Virtually

Personalized Medicine in GIST Registry Webinar, Fundación GIST Chile

Denisse Montoya, Director, LRG Patient Registry

On November 22, 2021 Patient Registry Director, Denisse Montoya, presented at a webinar entitled "Personalized Medicine- Mutations in GIST Patients" which was hosted by Fundación GIST Chile.

Denisse presented the mutational data collected from the Life Raft Group's Patient Registry and was able to discuss the importance of mutational testing as a part of personalized medicine in GIST.

Dr. Marcelo Garrido, a GIST expert from La Clínica INDISA, Santiago, was also on the panel. Together, he and Denisse stressed the importance of mutational testing and its impact on overall survival, treatment plan optimization, and risk of recurrence. Additionally, the webinar had a Q&A where oncologists and patients were able to ask questions in regards to the many factor of mutational testing. The objective of this webinar was to spread awareness of mutational testing and the road it paves toward personalized medicine among oncologists and patients. Webinar moderators were Piga Fernández and Carol Schoihet.

Download to view: <https://we.tl/t-LUJA30WSEQ>



Sarcoma & Melanoma Update 2021, India Sahibjeet Kaur, Patient Registry Supervisor

In November 2021, Sahibjeet Kaur was invited to present virtually at the Sarcoma & Melanoma Update 2021. This conference was held in India with 40 leading sarcoma and melanoma medical professionals who presented on varying topics. For GIST, Dr. Jay Mehta from India presented on mutational testing, "Not doing mutation analysis in GIST-crime or passable".

Sahibjeet presented on research and support for the GIST community, "Patient support groups in GIST - a catalyst for GIST management and research". She emphasized the importance of support within the community, the benefits of joining the LRG Patient Registry and how The Life Raft Group, through its vision, is a global leader in support, education and research. The keynote lecture on GIST was presented by Dr. Jonathan Trent, entitled "Recent advances in metastatic GIST". Dr. Trent discussed new drugs and treatments for patients with advanced GIST.

The conference had over 120 participants who listened to these updates and actively participated. Dr. Sameer Rastogi, a leading GIST specialist at AIIMS, New Delhi, India said, "This was the only conference in India in the last few years that has included GIST as a topic. Rare tumors are not commonly discussed in Indian conferences. Let's hope people would become more conducive to collaboration!"

GIST Collaborative Tissue Bank

- The GIST Collaborative Tissue Bank brings together GIST researchers and GIST patients in a unique partnership with the goal of accelerating research outcomes
- Patients who join our tissue bank are also required to be part of our patient registry
- This biorepository is designed to:
 - Allow multiple researchers to share rare tissue
 - Provide patients with the opportunity to reach leading researchers with a tissue donation
 - Maintain patient privacy: all identifying information is removed
 - Connect clinical GIST history through our patient registry with each tumor sample held in our tissue bank
 - Maximize the value of donated tissue and research time



LRG Staff Presenting Around the World Virtually, cont'd



NORD Rare Disease Day:

Rob Taylor, LRG GIST Mentor & GIST Patient Advocate

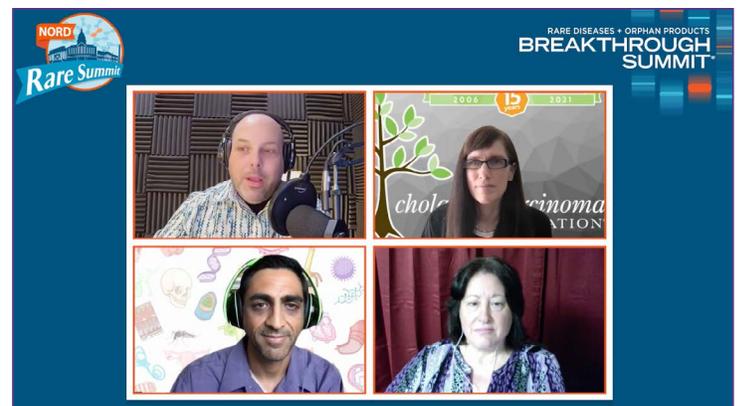


Rare Cancer Day, September 30th was marked with this webinar by NORD (The National Organization for Rare Disorders). GISTer Rob Taylor discussed a rare disease patient's access to treatments & services with a panel of experts in the webinar "Rare Cancers: Breaking Down Barriers to Diagnosis, Treatment and Research".

NORD Rare Disease & Orphan Products Breakthrough Summit 2021

Carolyn Tordella, Assistant Director of Communications

In late October, Carolyn participated on a panel entitled "Advancing Rare Cancer Awareness & Education Among Healthcare Professionals" which aired October 19th at the annual NORD Summit. which included Stacie Lindsey of the Cholangiocarcinoma Foundation, and Rishi Desai, of Osmosis, The panel discussion & Q&A was moderated by Matthew Zachary, the podcast host of "Out of Patients".



Panelists explored educational gaps among healthcare providers and innovative ways to provide targeted information on rare cancers and then answered questions from the audience. Carolyn illustrated how the Life Raft Group shares information with healthcare professionals through webinars, Project Surveillance, and virtual tumor boards coordinated by the LRG.

Attention International GISTers: Did you know about this Adjuvant Trial?

Trial title is, "Three Versus Five Years of Adjuvant Imatinib as Treatment of Patients with Operable GIST." Trial is open across Europe and has now expanded to Australia.

<https://gicancer.org.au/clinical-trial/ssgxxii/>

Trial investigator: Professor John R. Zalcborg, Alfred Health Head, Cancer Research Program, Public Health and Preventive Medicine

Contact: ssgxxii.study@sydney.edu.au

Bayer Pharmaceuticals & The Life Raft Group-Profit, Announce Innovative Collaboration to Accelerate Cancer Research for GIST Patients



Bayer Pharmaceuticals, working with The LRG, has extended a research collaboration to broaden access to comprehensive genomic testing for Gastrointestinal Stromal Tumor (GIST) patients. This collaboration aims to advance precision medicine in oncology and use comprehensive genomic testing to identify patients in the United States who may benefit from personalized care.

Comprehensive genomic testing, also known as biomarker testing or molecular testing, is a crucial step in understanding the genomic factors that play a role in establishing a GIST diagnosis. There are different types of comprehensive genomic testing: the most common tests are basic mutational testing and advanced next-generation sequencing. These tests may help identify alterations, or changes, within DNA and/or RNA of cancer cells that determine how a tumor behaves or why it grows. Basic mutational testing focuses on testing specific genes like c-KIT, PDGFRA, and BRAF. Advanced next-generation sequencing may test a broader range of genes, usually between 5-500+ genes, including neurotrophic tyrosine receptor kinase (NTRK) gene fusions. The results can help healthcare providers match patients with available treatment options or clinical trials. Finding the right therapeutic can be a turning point in the treatment journey of a GIST patient.

Criteria for patients to participate in this program includes: be a U.S. resident, be or become a part of the Life Raft Group GIST Patient Registry, have a treating oncologist, must not have had any type of prior comprehensive genomic testing (basic mutational testing or next-generation sequencing), or have previously been identified with wildtype c-KIT or PDGFRA results from basic mutational testing. This collaboration is an example of the vital role patient advocacy groups play in bridging the gap between researchers and motivated patient populations willing to be part of innovative studies.

"As part of our commitment to precision oncology, we believe identifying NTRK patients early through comprehensive genomic testing is a critical step in the cancer diagnosis of oncology patients experiencing metastatic disease, as it helps physicians understand the underlying drivers of tumor growth and can inform the treatment approach," said Iain Webb, M.D., Vice President, U.S. Medical Affairs, Oncology at Bayer. *"That is why we are pleased to collaborate with The Life Raft Group to increase the availability of comprehensive genomic testing for GIST patients to potentially uncover NTRK gene fusions and provide options for those who may benefit from precision oncology treatments."*

You can read more about this collaboration at:

<https://liferaftgroup.org/2021/10/tissue-testing-project/>

For more information on how to obtain testing, please contact Denisse Montoya, dmontoya@liferaftgroup.org

LRG Mention Noted in NIH Newsletter

A collaboration with MyPART and the LRG is detailed in this newsletter from the NIH concerning their work in SDH research. To view the entire, original newsletter visit the <https://content.govdelivery.com/accounts/USNIHNCI/bulletins/2fa5819>

The NIH will be holding an in-person Pediatric and Wildtype Clinic in September 2022 for the first time since the pandemic began. **Clinic Dates:** Sept. 14-16th, 2022

To Register: <https://ccr.cancer.gov/pediatric-oncology-branch/gist-clinic/registration-en>

Earlier Detection of Cancers in Patients with SDH Gene Mutations and Collaboration with The Life Raft Group

MyPART physician and researcher, Dr. John Glod, was recently awarded the NCI Center for Cancer Research Staff Scientist/Staff Clinician Research Award for his research project proposal, “Early Detection of Cancer in Patients with Germline SDH Deficiency.” Through this project, Dr. Glod and his team aim to develop a screening method to detect cancer non-invasively in individuals with mutations in the gene succinate dehydrogenase (*SDH*) by looking at [circulating free DNA](#) and other metabolites in their blood and urine. People with germline *SDH* mutations have a higher risk of cancer, including [pheochromocytoma](#), [paraganglioma](#), [gastrointestinal stromal tumors \(GIST\)](#), and in rare cases, renal cell cancer. The current approach for monitoring these patients for cancer includes MRI imaging and looking at blood and urine samples. Dr. Glod’s proposed approach to monitor circulating free DNA may allow for earlier detection of cancer in patients with *SDH* mutations and would be helpful in monitoring individuals who may have a family history of cancer.



Gastrointestinal stromal tumors, or GISTs, are rare tumors that grow in the digestive tract. In 5-7.5% of patients, these tumors have mutations in the gene for *SDH* (succinate dehydrogenase). GISTs with *SDH* mutations do not respond to available therapies, such as Gleevec, that are used to treat more common forms of GIST that do not harbor *SDH* mutations. The Pediatric Oncology Branch has a long history of working with the advocacy organization, [The Life Raft Group](#), to bring GIST patients to the NIH Clinical Center for the [Pediatric and Wild Type GIST Clinic](#). Patients are able to meet with experts from inside and outside of NCI, receive recommendations for their treatment, contribute to clinical research, and share their experiences with each other. NCI's collaboration with The Life Raft Group has been instrumental in bringing patients together and pushing GIST research forward.

Perspectives from The Life Raft Group:

The Life Raft Group has a longstanding commitment to finding effective treatments for young patients with SDH-deficient GIST. From the early days of our collaboration with the NIH to establish the Pediatric and Wildtype GIST Clinic to the creation of our Pediatric and SDH-Deficient GIST Consortium, we have been excited about projects, like Dr. Glod’s, that have the potential to impact this population. “I have been participating in the NIH Pediatric and Wildtype GIST Clinic for over ten years and it is encouraging to see the passion of the NIH faculty offering innovative ideas to accelerate progress in research for this rare disease community,” says Vice President of Programs of the Life Raft Group, Sara Rothschild.



New Horizons 2021

The New Horizons GIST Conference was held virtually October 20th-22nd and focused on sharing and discussing critical information about GIST that impacts the global GIST patient and medical communities. Participants had the opportunity to interact with leading GIST experts, learn new medical and scientific information about GIST, exchange best practices and discuss advocacy issues.

This year's New Horizon's event included not only medical professionals and representatives from patient advocacy organizations from around the world but also patients and caregivers from across the globe. Presenters covered topics such as Current Treatment Options, Best Practices for Advocacy, Global Access, Research Updated and Patient Stories.

The Conference had over 100 participants from 27 countries.

All the videos and resources from the conference are available at:
<https://liferaftgroup.org/new-horizons-2021/>



Thank you to our sponsors:



Navigating the Holidays

By Mary Garland, Director of Communications

Holidays can be a challenge. There may be pressure to recreate a 'Norman Rockwellesque' experience with the perfect turkey and many happy, family photos in holiday-themed pajamas. Or celebrating Hannukah with latkes made just like your grandmother's, or buying the perfect gifts for everyone.

Even if you don't celebrate a seasonal holiday, this time of year may trigger feelings of sadness as daylight is shortened and the seasons change. It is a time when it is especially difficult for those who have experienced losses - of a loved one or a loss over the way things used to be 'pre' - pre-pandemic or pre-cancer diagnosis, etc.

There is no magic pill to make the holidays and this season picture perfect, but here are a few tips that can help navigate the season:



Determine what will be your most difficult challenges. Make a list and check it twice. Consciously decide to avoid the difficult or develop a strategy to help you through, like attending a social occasion, but only staying briefly. Set boundaries that are right for you.



Change traditions that trigger memories and feelings of sadness. Participate in things that will bring you joy. Don't be afraid to have some fun. It is both okay to honor old traditions and to make new ones. Making new memories does not erase old ones.



Talk about your feelings with a trusted friend. You may experience survivor guilt if your loved one or a fellow GISTer has passed away. You may hesitate to celebrate the holidays. Don't bury your feelings. Plan to include an activity that honors your loved one's memory.



Give yourself permission to grieve. You may feel pressured to join holiday activities when all you honestly want to do is have a good cry. Give yourself permission to cut back on the number of events this season. It is important to feel those feelings when you feel them. Releasing your grief helps you to not stay stuck.



Create your own list of coping strategies. Make a list of what helps you when you are feeling sad or anxious. Call a friend, take a walk, practice yoga or meditation. Whatever works for you, carve out time to use these tools.



Reach out for help. There is no shame in asking for help. If you feel overwhelmed with negative feelings, there are resources available. Having a trusted friend to speak with is a great first step, but professional help is only a call away.

And remember that you are never alone!

Our GIST community provides many opportunities for you to share your thoughts and feelings, and to reach out to others. Our email community [GIST Chat](#), our [GIST Mentor program](#), and our [virtual support groups](https://liferaftgroup.org/event/) are here for you during the holidays and all year long.

A banner with a light beige background. On the right, a hand holds a small glass jar containing coins, with a red heart on top. An orange rectangular box on the left contains the text "Fundraising News" in white.

Fundraising News

By Jessica Nowak, Director of Outreach & Engagement

Night to Fight Cancer Online 2021: Part 2

While the world continues to navigate the ongoing changes of the COVID Pandemic, our fundraising and awareness efforts for GIST patients have never stalled. Our 2nd Night to Fight Cancer (NTFC) Online, hosted by LRG Board President Jerry Cudzil and Matthew Knopman, was held November 18th 2021. We partnered once again with Poker4Life (an organization that hosts charity poker tournaments) to make this another successful fundraising event.



The event had over 60 registrants who gathered virtually for a night of fun and fundraising. Early-bird registrants received a custom NTFC Online bottle of wine to enjoy with our hosts during the night's opening toast before the start of the tournament. Our guests were excited to play and connect again this year with friends from all over the country. At the end of a very exhilarating game the winners of the night were: Keith Kalnick won 1st place, Jerry Cudzil took 2nd place and Art Ringness placed 3rd. Congratulations to our winners!

Thank you to our sponsors: Bank of America, Goldman Sachs, RBC, Morgan Stanley, Cantor Fitzgerald, Credit Suisse, Trumid, and Ronnie Matteo. Thank you also to the team from Poker4Life for helping us bring our NTFC Community together again.

These funds enable the LRG to continue our mission to enhance the survival and quality of life for patients and caregivers living with GIST.

Research News: LRG Medical Advisory Board Member Dr. Sameer Rastogi publishes paper with AIIMS colleagues

The study entitled, "Carney's triad in an adult male from a tertiary care center in India: a case report," focused on the various manifestations of Carney Triad with an emphasis on the management of wild-type succinate-dehydrogenase-deficient gastrointestinal stromal tumor. This study is the first ever major paper on GIST from India. As per the study, "Literature regarding Carney's triad is scarce, especially from the Indian setting. Our report aims to highlight the various manifestations of this syndrome with emphasis on management of wild-type succinate-dehydrogenase-deficient gastrointestinal stromal tumor."

View the study here:

<https://jmedicalcasereports.biomedcentral.com/articles/10.1186/s13256-021-03149-x>



The Life Raft Group is grateful to our GEM Donors for their monthly commitment to the work we do with GIST patients & GIST research. Together we will keep patients informed, find more, effective treatments faster, and help patients and caregivers thrive on this GIST journey.

Opal Level

John Driscoll
Linda Gosser
Susan Migneault
Elizabeth Skree
Charlie Grana-Benn



Ruby Level

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 Level

Colleen Carney
Gilbert Tisdale
Alberta Tate
John Van Hise
Danielle Williams



Emerald Level

Robert Sholiton
Saeed Foudeh



Diamond Level

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

Thank you for your generosity!

Want to become a GEM? <https://liferaftgroup.org/donate-2/>

Thank you to our GDOL sponsors for 2021!



Thank you to our major donors for October & November

Iris Berke

The Ben & Emily Lerer Charitable Gift Fund

Cantor Fitzgerald Relief Fund

BST Consultants

Benji Cheung

Anne Dahne

Paul Faust

Fidelity Charitable

Taylor Ford

Bryan Hector

Claudia & John Link, Inc.

J.P. Morgan Charitable Giving Fund

Chet Malhotra

Ronald Mateo

Lisa & Eric Medhus

Steven & Alison Murphy

Cynthia Russell

Benji Serra

Christine Walters

Martha Zielinski

What's Happening?



See all registration links on our Events page: <https://liferaftgroup.org/event/>

Support Groups

Virtual - GISTer Group

First Tuesday of the Month
6pm-7:30pm ET

Virtual - Caregiver Group

1st & 3rd Wednesdays
1pm-2pm ET

Virtual - New Member Orientation

Once a quarter - see calendar

Upcoming Webinars

The Value of Biomarker Testing:

Case Studies Across Institutions

January 6, 2022, 12-1PM ET

GDOLs

GDOL Arizona - Virtual

January 27, 2022, 2PM MT, 4PM ET



Make a Note!



LIFE FEST NEW ORLEANS 2022

Friday July 29th - Sunday July 31st

Book your hotel today!

Life Fest is a unique event where hundreds of patients and caregivers come together for a weekend to interact with each other and the medical and scientific communities that serve them.

<https://liferaftgroup.org/event/lifestest2022/>

April 9th, 2022, 8am, Verona Park
NJ GIST Do It Walk

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

Sponsor this event: jnowak@liferaftgroup.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, 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/Patient Registry Associate	Maeven Luedke
Web Associate	Eddie Delgado
Fiscal Director	Robin Elia
Operations Manager	Helena Mattioli
Patient Registry Associate	Jordanne Nelson
Patient Registry Associate	Antoinette Pauwels
Consultants	
Global Relations Coordinator	Piga Fernández
Grant Writer	Rebecca Pauley

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 Volunteering?

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

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	Phillippines	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	Norway	Frode Homb	Turkey	Haver Tanbay
France	Estelle LeCointe-Artzner	Pakistan	Sobia Wali Muhammad	U.K.	Jayne Bressington
Germany	Markus Wartenberg	Peru	Karla Ruiz de Castilla	Uruguay	Verónica Armand Ugón
Greece	George Constantinou			Venezuela	Angel Selena Rodriguez
Guatemala	Silvia Castillo de Armas				

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