

GISTGive

Every dollar donated goes to supporting GIST patients & furthering GIST research.



What Do We Do?

RESEARCH



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

PROGRAMS



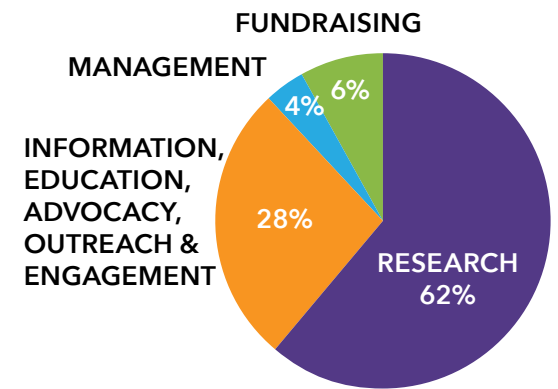
- Consult with over **50+** patient per week.
- Facilitate a **GIST Mentor Program** serving over 300 patients & caregivers globally.
- Host **5 U.S. GIST Days of Learning** yearly at major cancer centers.
- Conduct monthly educational webinars online.
- Host the biennial **Life Fest**, our premier educational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

GENERAL



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

Where Does Your Money Go?



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

Quick Facts

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

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

OVER **100** SUPPORT GROUPS HELD PER YEAR



Donation Link



VENMO

LRG REPRESENTATIVES SUPPORT PATIENTS & CAREGIVERS IN

50 STATES

53 COUNTRIES

OVER **20,000** PEOPLE SERVED IN OVER **105** COUNTRIES



Member Stories



Dr. Monica Anderson had no symptoms. In the middle of the night and alone, she was told they found a mass. This was the lowest point in her GIST journey. She felt as if the world stopped on its axis. "I cried for days. I didn't know I could make so many tears."

Another low point for her was a recurrence at the two-year mark, "I felt like I was doing everything the medical professionals told me. I followed the rules." But in spite of following courses of Gleevec, Sutent, Tasigna and Stivarga, with side effects that were challenging, she had to undergo a difficult surgery back in December. All of this was in the middle of promoting her book, being a good mom and grandmother and mentoring others. Balancing all her feelings at this time was challenging.

The high point of her GIST journey has been coming through two major surgeries, and meeting people, especially through the LRG. By talking about GIST, not only is she raising awareness, but she is also empowering herself.

'Dr. mOe' is a dentist, an author, podcast host, and featured TED Talk speaker, LRG Board Member and active GIST Advocate.



MaKayla, diagnosed in 2011 has epigenetic SDHC-deficient GIST, no treatment protocol available.

MaKayla's GIST education began at 14 years old, when she underwent an endoscopy to uncover the cause of ongoing GI distress. The tumors doctors discovered were removed with clear margins, and though discussed, no treatments were begun at that time. Her scans remained clear for four years until mets were discovered on her stomach and on her liver. They appeared indolent (slow growing), and monitoring was advised, rather than surgery.

Since then, MaKayla has endured several extensive surgeries and an abundance of side effects including severe gastroparesis, reactive hypoglycemia, and Postural Orthostatic Tachycardia Syndrome. She feels that aside from the cancer itself the complications from the surgeries have caused the most serious issues for her. She has persistent hydration and nutritional issues, sometimes requiring a feeding tube, and has had to endure many procedures to combat these complications over the years.

MaKayla is an active nature lover and creative as well as a vocal GIST advocate & LRG volunteer. She is grateful that despite the lingering issues from having chronic illness and living with GIST, she is living with no evidence of disease.



Santy DiSabatino - "I remember the first time I heard the word GIST. I was in the recovery room after having a colonoscopy and endoscopy done due to what was perceived as a stomach issue (not truly related to the GIST) and due for a ten-year colonoscopy. I was in the recovery room

and the surgeon said: "Your stomach is fine. You have an infection in your intestine which two antibiotics should clear up, and you have a 14 mm GIST. My office will call you in a few days and schedule you for a six-month endoscopy. If the GIST has grown at that time, I will remove it and your gall bladder". I had no gall bladder pains; tests just showed it was functioning at 19%."

The surgeon turned and walked out. I thought "What is a GIST"? I went home and immediately Googled it. I was in shock! I had no idea it was a tumor. I also found the website of my godsend, The Life Raft Group!

I discovered & joined the LRG, who set my mind at ease and made me feel cared for. Thus began a lifelong relationship with the LRG. All staff at LRG when I call ALWAYS listen to what I have to say, what may be troubling me, or what questions I may have. They do their best to answer all of them or find someone who can. They are caring all the time.

Today, Santy is living with no evidence of disease and is a GIST Advocate, Mentor & LRG Board Member - "If I have any advice for fellow GISTers it would be to keep fighting on, and ALWAYS remember to be your biggest advocate and supporter for your health. If you feel uneasy about a doctor's opinion, advice, or care plan, email the LRG support group for advice. People in the group have GREAT ideas and advice. Many have been in our "shoes" before and their experiences and advice are priceless. So are their constant daily words of encouragement."



Maria, Ireland - "All I wanted was to feel better."

In April of 2020, at the height of the global pandemic, the LRG was contacted by a young mother whose seven-year-old daughter Maria was diagnosed with GIST. Maria's primary treatment team suggested a radical operation that would be severely life-altering for this young girl.

The LRG gathered experts from around the globe for a virtual tumor board to review Maria's case and assisted in formulating a less invasive course of treatment for the young girl, putting her on the path for a better life.



bit.ly/LRGMemberStories

