The Life Raft Group: Gastrointestinal Stromal Tumors (GIST)
Advocacy, Data, Research & Collaboration

MISSION

The Life Raft Group (LRG) is committed to enhancing the survival and quality of life for people living with GIST, and other rare diseases, through patient-powered research, education and empowerment, and global advocacy efforts. Our vision is to empower a future fueled by data, guiding our journey toward cures for rare diseases.

RESOURCES

The LRG offers a variety of resources aimed at empowering and supporting GIST patients and caregivers globally.

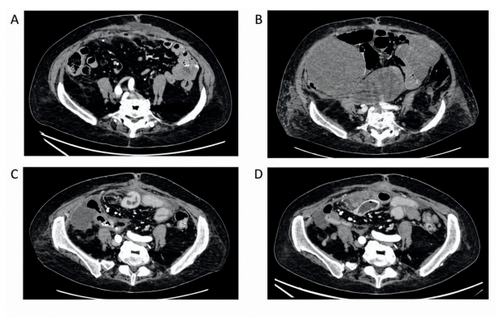
Available resources include:

- **GIST Chat** – A private chat group offering peer support.
- **Mentorship Program** – Connects patients with experienced mentors.
- **GIST Specialists Directory** – A database of experts in GIST care.
- **Clinical Trial Database –** Information on current clinical trials.
- **Personal Case Manager –** One-on-one support for personalized care.
- **Support Groups –** Peer-led support networks
- **In-Person & Virtual Educational Events** – Learning opportunities for patients and caregivers.
- **Alianza GIST** – A Latin American program to enhance GIST survivorship in the region.



TUMOR BOARDS

The LRG hosts **virtual** tumor boards where experts collaborate on complex GIST cases. It also features an email group for physicians to share urgent cases and receive rapid expert feedback, enhancing patient care through real-time collaboration.



Virtual Tumor Board Case - October 2026

PATIENT REGISTRY & TISSUE BANK

The LRG Patient Registry is an IRB-approved, patient-driven, natural history study (NCT07697248) utilizing advanced technology to collect comprehensive data and tissue from individuals with GIST. This global database supports research, improves patient outcomes, and deepens the understanding of GIST.

3,105 GIST Patients Enrolled*

54% FEMALE

45.9% MALE

*0.1% NOT REPORTED

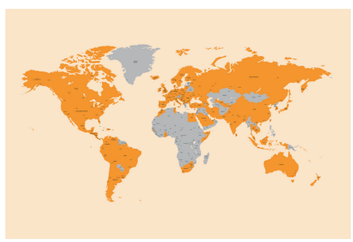
TOP 3 PRIMARY TUMOR LOCATIONS*

Stomach **46.2%** **1435**

Small Intestine **37.8%** **1174**

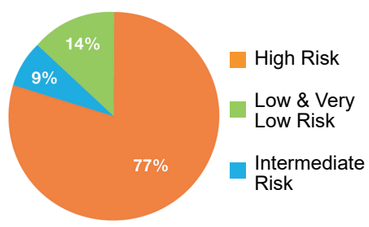
Rectum/Anus **2.9%** **92**

* Data reflects cases with localized presentation at diagnosis only



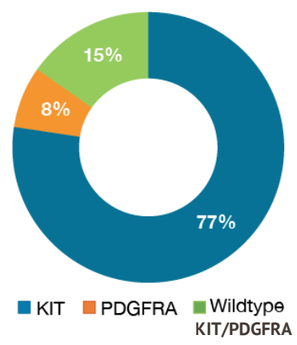
TOP COUNTRIES:
1.USA 2.Canada 3.United Kingdom 4.Netherlands 5.India

RISK OF RECURRENCE



Modified NIH Method used to calculate risk.

TYPES OF PRIMARY MUTATIONS:



(**Wildtype KIT/PDGFRA** is defined as any mutation that is without a KIT or PDGFRA mutation. It includes BRAF, NF1, NTRK, SDHA, SDHB, SDHC, SDHD.)

UPCOMING NEW REGISTRY FEATURES

Our **new & improved LRG Patient Registry**, launching in 2026, will set a new standard for GIST research and patient care.

This **optimized platform** will offer groundbreaking features to provide researchers with access to **de-identified patient data, raw genomic information, and tissue samples,** all enhanced with **dynamic data visualization tools** for deeper analysis.



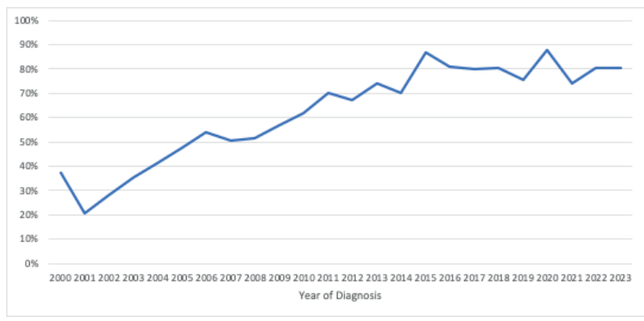
Key advancements include:

- **Cutting-edge integration** of electronic medical records (EMRs) with patient-reported data, enabling a holistic view of the patient's journey.
- **Live access to patient-reported outcomes** that reflect the real-world quality of life and treatment effectiveness.
- **Personalized clinical trial matching** to streamline patient recruitment and accelerate advancements in treatment options.

ONGOING COLLABORATIONS AND RECENT ACCOMPLISHMENTS

- SDH Biobank and Centralized Database
- Global GIST Risk Collaboration (GGRC)
- NIH Succinate Dehydrogenase (SDH) and Ultra Rare GIST Clinic
- Re-thinking placebo and embracing synthetic control arms
- TMA development to continue to explore potential biomarkers
- Developing guidelines for better patient identification and management in GIST
- Mutational Testing initiative to improve precision medicine

Mutational Testing Rate Increases in LRG PR Members



PARTNER WITH THE LIFE RAFT GROUP TO ADVANCE GIST RESEARCH

The LRG is committed to driving progress in GIST research, and we invite researchers like you to collaborate with us. Our Patient Registry provides a unique opportunity to access real-world patient data enabling insights that can accelerate the discovery of new treatments and improve patient outcomes.

By partnering with the LRG, you will:

- **Access valuable tissue and patient-reported data** that reflects a complete real-world experiences helping you explore patterns, treatment responses, and long-term outcomes.
- **Contribute to meaningful research** that can directly impact patient lives while advancing the scientific understanding of this rare cancer.

TOGETHER, we can expand the horizons of GIST research and move closer to breakthroughs that save lives. Let's transform the lives of GIST patients together.

JOIN US TODAY!
Contact The Life Raft Group to discuss collaboration opportunities.



The Life Raft GROUP

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