About The Life Raft Group

Our Mission
The Life Raft Group is committed to enhancing the survival and quality of life for people living with Gastrointestinal Stromal Tumor (GIST), and other rare diseases, through patient-powered research, education and empowerment, and global advocacy efforts.

What is GIST?
Gastrointestinal stromal tumors (GIST), usually found in the gastrointestinal tract, belong to a rare group of cancers called soft-tissue sarcomas. Although GIST is often spoken of in the singular, it is actually a family of cancers that encompasses “adult”, SDH/pediatric, and familial (hereditary) forms.

What We Do

Patient Support

Education & Training Programs
Through our website, educational materials, webinars, and GIST Days of Learning (GDOLs), we empower patients to have meaningful involvement in their care.

GIST Mentor Program
A program to support people with GIST and their loved ones as they navigate through diagnosis, treatment and recovery.

GIST Chat
Our closed online community, GIST patients and caregivers are free to discuss and share information and thoughts.

Research
We advance GIST research through a dual approach, combining traditional lab studies and clinical trials with patient-powered real-world evidence.

Our initiatives include:

LRG GIST Patient Registry
With over 2500 records from 90+ countries, our registry tracks patients across institutions, offering centralized record-keeping and personalized support. Our rigorous quality control ensures valuable data for peer-reviewed journals.

GIST Collaborative Tissue Bank
This bank holds 800+ tissue samples, facilitating the acceleration of GIST research.

Virtual Tumor Boards
Originally developed to support the NIH Pediatric and Wildtype GIST Clinic, these case reviews aid physicians worldwide in treating challenging cases.

Global Surveillance Team
A network of global physicians and researchers who collaborate regularly on topics related to patient survival.

Patient & Caregiver Support Groups
These virtual & in-person groups meet to encourage and support each other through their cancer journey.

Advocacy
From facilitating access to treatment to affecting change in legislation and treatment guidelines, the LRG has a global footprint.

Learn More:
liferaftgroup.org
email: liferaft@liferaftgroup.org