

The LRG Patient Registry



The Life Raft Group Patient Registry is a structured database that collects comprehensive information about individuals diagnosed with GIST. The purpose of a registry is to facilitate research, improve understanding of the disease, track patient outcomes, and ultimately enhance patient care. Our objective is simple: to deepen our understanding of GIST in order to provide assistance and help you thrive, along with others impacted by this condition.

As part of the patient registry, you're not just sharing your story—you're becoming part of something bigger. With over 2800 patients and caregivers from all around the world, we're learning new things about GIST every day. Your experience could be the missing piece that helps us understand this disease even better. Please know that your privacy is protected, and no identifiable information is used in research studies.

Your participation also creates a legacy of valuable knowledge that not only benefits your own understanding and management of the disease but also helps guide and support future GIST patients around the world.

By joining the Registry, you will have:

- **Access to Cutting-Edge Information:** Learn of the latest developments and insights in GIST research and treatment options, empowering you to make informed decisions about your care.
- **Individualized Support:** You will receive personalized support from our patient coordinator, who will provide guidance based on your experiences and needs, helping you face day-to-day life with greater clarity and confidence.
- **Access to GIST Specialists:** Connect with GIST specialists and healthcare professionals who have expertise in the diagnosis and treatment of GIST, ensuring you receive the highest quality of care and support.
- **Community Connection:** Connect with a supportive community of individuals living with GIST, providing valuable peer support, shared experiences, and a sense of belonging.
- **GISTory – Your Medical History on One Page:** By joining the Registry, you receive your GISTory — a summary of your medical and clinical history of GIST that makes it easy to track your diagnosis, treatments, and progress in a clear and accessible way.
- **Privacy and Security:** Your data is protected by multiple security measures to ensure privacy and confidentiality, maintaining the highest standards of data security and compliance.
- **Empowerment Through Data:** By contributing your data to our registry, you empower researchers and healthcare professionals to better understand GIST by giving patients a voice, ultimately improving outcomes for all individuals living with GIST.
- **Participate in Surveys:** You will have the opportunity to participate in surveys and studies aimed at gathering valuable insights into the experiences and needs of patients, contributing to the advancement of knowledge and care in the field.
- **Clinical Trial Matching:** Explore opportunities to match with clinical trials and research studies that may offer innovative treatment options or contribute to advancements in GIST care.

Most importantly, by contributing to our registry, you'll have the opportunity to leave a lasting legacy of knowledge, driving transformative changes in the lives of others. With your help, we move closer to a deeper understanding of GIST. Together, we can move GIST research along and continue to save lives.

**For more information on joining the patient registry,
please email us at: patientregistrydepartment@lifteraftgroup.org**