

GET INVOLVED. MANAGE YOUR GIST CARE. BUILD YOUR TEAM.

Choose a Patient Advocate

Your patient champion could be a spouse, child, parent, or anyone with whom you share a close relationship. This person will help support you not only emotionally, but also will help in talking with doctors, finding medical resources, and will act as a patient advocate.

Find a GIST Specialist

When seeking a new oncologist, ask the scheduling coordinator if the doctor under consideration treats GIST patients regularly.

- Do they treat both adult and other rarer mutations?
It is important for you to see a doctor who has experience treating your specific GIST classification.
 - Adult GIST: Mutations detected in the KIT or PDGFRA gene.
 - If mutations are not detected in the KIT or PDGFRA gene, then it is considered Wildtype or Pediatric GIST.
- For help finding a specialist, please visit:
<https://liferaftgroup.org/gist-specialists/>

Find a Nutritionist

After starting a new treatment or having surgery, it is recommended to monitor your dietary intake and ensure you are absorbing and retaining enough vitamins and nutrients.

- Record all post-operative meals, treatments, and side effects to identify any patterns.
- Contact your insurance provider and speak with your doctor about coordinating an appointment with a Registered Dietician in your network.

Connect with other GIST patients

Connecting with fellow patients and caregivers will provide emotional support and other resources to support GIST management.

- Inquire about your physician's GIST patient network.
- Connect with others through the LRG's GIST Chat, an e-mail community with patient and caregiver participants.
- Match with a GIST mentor who has gone through a similar journey for social and emotional support.

Please see our membership application to begin the process:
<https://liferaftgroup.org/life-raft-group-membership-application-form/>

Organize Reports

Organize and maintain a detailed list of medication, dosages, side effects, and treatment and evaluation dates.

- Request a copy of every exam (bloodwork, CT, PET, MRI) and organize in a binder chronologically.
- Join the LRG Patient Registry: A database with specific features to keep a comprehensive record of all medical evaluations and treatment beginning with GIST diagnosis. For more information, contact the Data Management & Research team at patientregistrydepartment@liferaftgroup.org.