GIST/PRIME

The Life Raft Group Patient Registry

Working with GIST patients since the year 2000, the Life Raft Group realized the inherent value in patient-powered data, and utilized our membership's medical data and experiences to build a multifaceted and unparalleled patient registry. Combined with the support of the Patient Registry team, this tool has served to empower our patients to learn more and take charge of their own care, which has led to higher overall survival rates. Simply put, empowered and educated patients live longer.

GIST/PRIME™ is the LRG Patient Registry—allowing patients to update and even compare their records registry-wide through comparative charts. It captures their information over time and across institutional boundries.
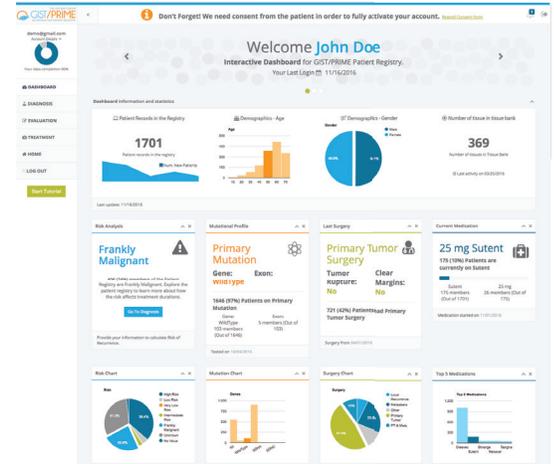
SUPPORTING PATIENTS

Keeps GIST medical records organized and up-to-date.

Patients receive individualized feedback on their care to help them and their medical providers stay current with the latest GIST treatments.

HELPING THE GIST COMMUNITY

Patients become part of the global GIST community by contributing their clinical data to build the largest GIST database in the world.

Using this data, the LRG identifies treatment and response trends that can improve patients' lives now.

ACCELERATING RESEARCH

Patients can participate in cutting-edge research.

In addition to clinical data, patients can also donate tissue to the accompanying GIST Collaborative Tissue Bank and help unlock the next research breakthrough.

KEY ELEMENTS

GIST/PRIME™ gives GIST patients and caregivers a tool to monitor their GIST history and contribute their data, making it easier for them to work with their medical team to improve their medical care and enabling researchers to glean much more meaningful data for research.

- The Dashboard displays Registry demographics and how the patient relates to others within the system. It can also calculate Risk of Recurrence and give valuable feedback on how the patient's individual milestones can help them optimize their care.
- The Mobile Application brings interactive GIST management right to the patient's phone with push notifications that remind the user to quickly update their records, which they can do anytime, anywhere.
- The GISTORY is an exportable, printable document that provides a comprehensive summary of a patient's GIST medical history, helping facilitate efficient communication between patients and multiple medical providers.
- Security & Privacy: Institutional Review Board-approved, GIST/PRIME™ follows all HIPAA protocols and includes a trained staff and Privacy Officer. Data is housed on a SQL platform, and relies on encryption and multiple layers of authentication

www.GISTPRIME.org