Since the beginning, the Life Raft Group positioned itself to empower patients and promote collaboration between those whose are singularly focused on improving the lives of anyone affected by gastrointestinal stromal tumor (GIST). It has easily bridged the gap between researchers and motivated patients who want to share their clinical histories and tissue to create new treatments and improve outcomes through its Patient Registry. The LRG has a proven track record of collecting and utilizing patient driven data and translating it into improved outcomes. The LRG GIST Patient Registry represents patient history collected over 15 years across institutional boundaries. Over this time, the registry has evolved into a state-of-the-art, structured query language (SQL), cloud based platform. Incoming members provide their full disease history and current condition in order to participate in the Patient Registry. Medical updates are regularly collected through various means, depending on the member’s preference. Examples of data fields collected include: Date(s) of diagnosis, initiation of treatment, initial and last reported daily medication dosages, and response to treatment. Demographic data includes sex, marital status, date of birth, country, ethnicity, date of death and primary tumor site. Outcomes are based upon response to drug therapy: no evidence of disease, shrinkage, stable disease, progression, or deceased.

In 2013, the LRG implemented the Institutional Review Board’s (IRB) informed consent process as overseen and approved by Quorum Review. Although existing members were technically grandfathered in under the prior rules, all living Registry members were contacted by phone and received notice and a copy of the IRB Protocol and Informed Consent by mail. Since then, new members must go through the informed consent process before admittance to the LRG GIST Patient Registry. With over 1,700 patient records, equally divided between men and women and spanning all age groups across the globe, the LRG GIST Patient Registry contains more data than any one GIST specialist would possess.

The Registry also includes a companion tissue bank, which links clinical information in the Registry to biological samples currently maintained at Stanford University. It currently includes 767 formalin-fixed paraffin-embedded tissue samples related to 396 individual patients. Patients whose tissue samples were added to the repository underwent informed consent allowing tissue to be used for research purposes. Taken together, the LRG GIST Patient Registry and the Tissue Bank provide the perfect interactive network to ask critical questions as they relate to the biology and treatment of GIST.