

Life Raft Group



Research • Support • Education

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Mission

The Life Raft Group (LRG) has a simple focus: to cure a form of cancer – GIST (gastrointestinal stromal tumors) – and to help those living with it until then.

The mission of the Life Raft Group is to ensure the survival of GIST patients through a comprehensive approach connecting individual patients' needs, the worldwide community of GIST advocates and the global health and research environment. This is accomplished through Research, Support and Education and Advocacy.

Strategy/Approach

- **Research** – The Life Raft Group funds and manages uniquely coordinated research initiatives that always keep the needs of the GIST patient foremost. The Life Raft Group is the only GIST advocacy organization with a dedicated research initiative led by a team of world renowned scientists and clinicians in GIST. The initiative is constantly analyzed to ensure their focus remains on finding a cure for GIST.
- **Support and Education** – The Life Raft Group provides support and education to patients and caregivers with GIST on an individual basis by providing one-on-one counseling sessions, local in-person meetings and a biennial meeting that gathers the patient, pharmaceutical community and medical professionals together in a supportive and educational setting. Education is also offered to the GIST community through videos and webinars, websites, Days of Learning, a worldwide GIST specialist database, a unique GIST-specific clinical trial database, newsletters and other materials.
- **Advocacy**– The Life Raft Group is an active presence in effecting change within the GIST community. Advocacy roles range from helping patients with treatment access issues on a one-on-one basis, creating regional groups in underserved areas in order to better inform and empower patients, championing patients' needs before government and policy makers and reporting on trends in treatment and survival to the world. The LRG continues to fight against the use of placebos in cancer clinical trials, and to advocate for mutational testing. The LRG has helped patients gain access to life-saving treatments in places such as China, Iran, Macedonia and Latin America.

The Life Raft Group maintains a **GIST Patient Registry** with over 1,500 participants that serves to provide the patient with a summary that will help them to better track diagnosis, treatment and scans.

The LRG **GIST Collaborative Tissue Bank (GCTB)** is a one-of-a-kind model that combines tissue with the patient's de-identified GIST history.

Research Portfolio

LRG's research model is representative of a new direction among disease-focused organizations to find cures by becoming actively involved in the research process. Its grants infrastructure holds each researcher accountable for specific results, redirects resources when research dead ends, and supplements resources when new needs arise.

Pathway to a Cure began in 2005 with the creation of a five-year strategic plan to find ways to counteract Gleevec-resistance in GIST. The project brought together a core group of the world's best GIST scientists and funded their collaborative research efforts, with a 0 percent cap on the administrative overhead and indirect costs for all grants. Cooperation, coordination, and accountability are the key factors to its success.

- **Phase I** (March 2006-June 2008) – Allocated \$2 million to researchers best suited to implement LRG's strategic plan.
- **Phase II** (July 2008-June 2010) – Awarded another \$2 million to researchers who successfully completed Phase I projects, committing funding for six months with non-competitive renewals conditioned upon receipt of satisfactory progress reports.
- **Project D-Day** (July 2010-present) – This two-year initiative supports research focused on sequencing the GIST genome, gene knockdown studies, or screens that will examine pathways essential for GIST cell survival, drug screening of GIST cells against large libraries of drug compounds, and validation studies where discoveries in previous research will be repeated for confirmation.

LRG also collects data from its member patients – a medical history upon joining and updates as they occur – for a master database through which it periodically conducts surveys on such issues as side effects and the quality of medical care.

Partnership Practices

The LRG engages with pharmaceutical companies, insurance companies, medical institutions, and policy makers to help patients gain access to clinical trials and to overcome financial and logistical obstacles to treatment.

The LRG partners with biotech and pharmaceutical companies to foster research.

Financials

The LRG is a 501(c)(3) non-profit organization. The latest financial information is from 2013.

- Year ending 12/31/2013:
- Revenue: \$1,450,331.87
- Grants: \$847,348.00
- Expenses: \$2,487,616.01
- Total assets: \$3,320,700.62

Key Accomplishments

- Allocated more than \$9 million to research over the past six years.
- Performed the largest known analysis of the GIST genome
- Ranked 11,000 genes in several GIST cell lines in order of their functional relevance for GIST
- Tested 127 compounds for their therapeutic value in GIST
- Working with several major genome centers to improve insertion/deletion mutation detection which is crucial to help identify more genetically-targeted tumor suppressors to GIST
- First to report on Gleevec effectiveness for GIST patients.
- Developed a new scale to allow patients to rate the severity of their side effects, and a study to evaluate the relationship between relapse and dosage levels.
- Screened and identified 7 of 27 compounds sensitive or resistant to Gleevec that could potentially inhibit GIST growth
- Created its own patient-driven database and published information about treatment efficacy in its newsletter and on its website, often ahead of traditional research reporting.
- Provided gratis mutational testing for patients who participate in the LRG tissue bank
- Expanded its tissue bank into Latin America providing the benefit of helping to identify misdiagnosis in 40% of cases
- Created a one-of-a-kind clinical trials database featuring GIST specific or relevant trials
- Released the first issue of The GIST Cancer Journal, the official journal of the LRG and the first academic journal devoted solely to GIST.

Leadership

The Life Raft Group is governed by an International **Board of Directors** and managed by a **leadership staff**.

- **Executive Director:** Norman Scherzer, nscherzer@liferaftgroup.org
- **Deputy Executive Director:** Roger C. Campbell rcampbell@liferaftgroup.org
- **Science Director:** Jerry Call, jcall@liferaftgroup.org
- **Program Director:** Sara Rothschild, srothschild@liferaftgroup.org
- **Strategic Planning Director:** Pete Knox, pknox@liferaftgroup.org