

Support *(continued from inside)*

for daily information and support and upon the LRG websites, and monthly newsletters for the latest news. Local LRG groups meet face-to-face in intimate settings across the world in cities such as Detroit, Chicago, Los Angeles, Dallas and Amsterdam. Hundreds of patients, caregivers and physicians contact the LRG office to seek information about treatment options and access to treatment. No one is turned away. The LRG's International GIST Specialist



Life Rafter's bond at a membership meeting.

Directory continues to grow as a source of lifesaving information for patients seeking medical expertise for this rare disease.

Research *(continued from inside)*

awards to implement this plan have gone to Catholic University (Leuven, Belgium), Dana-Farber/Brigham & Women's Hospital, Oregon Health & Sciences University/Portland VA Hospital, Memorial Sloan-Kettering, Stanford University, and the Cleveland Clinic.

LRG Research

The LRG's internal research, which draws upon information provided by patients, continues to discover important new information to further the survival and well-being of GIST patients. This internal research is designed to provide us



Dr. Jonathan Fletcher addresses the Research Team.

with information that is not currently available from clinical trials. The LRG was the first to publish that Gleevec was an effective treatment and that its side effects got better over time. Last year the LRG presented cutting

edge information about the relationship between the dosage level of Gleevec and the development of resistance. To strengthen this research, the LRG has created a more robust database. The LRG's pediatric GIST database, the largest in the world, continues to accumulate information about this critical subset of the disease.

Data is being collected to investigate the relationship between dosage level and preventive treatment, something which none of the ongoing clinical trials are addressing, to continue to study GIST treatment resistance, and to investigate underreporting of GIST cases.

A note about Life Raft Group research:

Dr. Daniel Vasella, CEO of Novartis described our research as follows: "The Life Raft Group ... has provided various people, patients, doctors, investigators with a unique



kind of data bank that cannot be replicated anywhere else, not even in patient trials."

LRG Research Team members listen intently to the new research model being presented.

LRG Resources

Copies may be requested by contacting the Life Raft Group Office or through the website.

- Email Community FAQs
- Financial & Logistical Resources
- GIST Pamphlet
- GIST Patient Registry
- GIST Specialist Directory
- Managing your GIST Care
- Mutational testing and Genotype Card
- Navigating GIST Clinical Trials
- Newsletters
- Pediatric GIST Pamphlet
- Side Effect Management

Contact Us

The Life Raft Group
40 Galesi Drive, Suite 19
Wayne, NJ 07470

Phone: 973-837-9092
Fax: 973-837-9095

www.liferaftgroup.org
E-mail: liferaft@liferaftgroup.org

Donate to the LRG

The Life Raft Group depends on the generous donations of its members and other supporters. Membership is free. Without the support of kind donors the LRG would be unable to provide the lifesaving services described in this pamphlet. Thank you.

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The Life Raft Group



MISSION

the survival of GIST patients

www.liferaftgroup.org

The Life Raft Group (LRG) is the world's leading 501-C-3 non-profit organization whose mission is to ensure the survival and well-being of patients and families with Gastrointestinal Stromal Tumor (GIST).

To accomplish this mission, the Life Raft Group devotes our efforts to five major program areas:

- Information & Education
- Surveillance
- Research
- Support
- Advocacy.

Information & Education

Providing the latest information to patients and doctors

Life Raft continues our efforts to strengthen the scientific and support content for our website, newsletter and online communities.

The LRG produces and distributes informational pamphlets for GIST patients. Life Raft also responds to correspondence and telephone calls from the newly diagnosed to those facing a recurrence.

A new online community is maintained solely for pediatric patients and their families. The LRG connects patients to local resources throughout the world through the Global GIST Network.



Two of the LRG's youngest members

Surveillance

Staying up-to-date on new treatments and clinical trials

The LRG aggressively tracks new drugs and compounds before they even enter clinical trials for GIST. We seek out and publish clinical trial information in our newsletter and website before any other trial listing service, private or government. We track these clinical trials via patient reports and evaluate the efficacy and side effects of the new drugs on an ongoing basis. We share this information with patients and doctors through our newsletter and website.



LRG's Board of Directors at a planning meeting.

Research

Funding research to find tomorrow's cure

Resistance Research Initiative

Armed with a generous start up grant from Novartis, the Life Raft Group began developing the first strategic research plan to find a cure for GIST. After many months of work assembling a world class research team, and building an innovative grants infrastructure to support it, we completed the plan and have posted it to our website. We successfully set a cap on indirect costs of 10% at every one of the grantee institutions. We created and maintain two tissue banks, one at Stanford for adult GIST and one at Memorial Sloan Kettering for pediatric GIST, with a common protocol for submitting tissue that is be used by both banks. We believe that we have



LRG's Resistance Research Team in Boston at a strategic planning meeting.

established a frame-work for unprecedented collaboration between researchers, including appointing team leaders who will coordinate their projects across institutional boundaries. Grant

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Ensuring that no one has to face GIST alone.

Support

Connecting patients and caregivers via the internet and in-person groups

The LRG hosted the first pediatric GIST meeting for the children and their families afflicted with this disease. This peer-to-peer networking is invaluable for pediatric GIST families trying to manage the care of a rare disease for a child.

The LRG co-founded and maintains a

key role in the coordination of the Global GIST Network which connects patients all over the world to resources available in their home country and language.

GIST patients and caregivers continue to count on the LRG online communities

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LRG members at the First Life Fest in Boston, Mass.

Advocacy

Overcoming hurdles to help patients access treatment



LRG staff meet with pharmaceutical companies to plan clinical trials.

Life Raft's advocacy efforts contributed to the federal government's decision to

cover Gleevec, the most effective oral drug therapy for GIST patients, under the Medicare Demonstration Act and under the comprehensive Prescription Drug Program. Life Raft continues its efforts to oppose the use of placebos in clinical trials for GIST patients for whom no other treatment alternatives are available. Pharmaceutical companies continue to reach out to the LRG for input and assistance in planning clinical trials for GIST patients.