

## Resources

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

- GIST Pamphlet  
(Also available in Spanish & Hebrew)
- GIST Specialist Directory
- Newsletters
- Pediatric GIST Pamphlet  
(Also available in Spanish)
- Navigating GIST Clinical Trials
- Annual Report

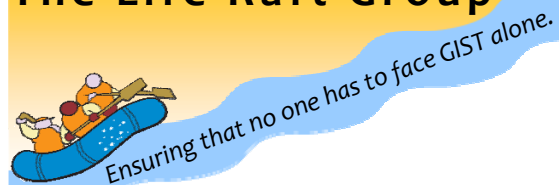
## Donations

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.

## Special Thanks

The LRG would like to recognize Steve Rigg for his work designing the LRG Access Database. He volunteered countless hours and was endlessly patient. Steve's wife has been battling GIST since 2002.

## The Life Raft Group



# GIST Patient Registry

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## Our Philosophy

Our goal is simple, a cure. Until that goal is achieved, we must maximize benefit from today's tools. Timely knowledge and information are key to achieving these goals. The LRG collects this information to allow us to share it with GIST patients and caregivers.

To this end, the Life Raft Group has created a unique Patient Registry. All of our information comes directly from patients or caregivers. Using this data we examine questions that are not being answered quickly enough by current trials or questions that are not being looked at in clinical trials. We monitor the latest treatments for early indications of a response. We look for treatment and response trends that can help our members reach tomorrow's cure. We reduce the lethal lag-time between discoveries of important data to communication.

Since the LRG is not limited by the design of traditional clinical trials, we have significantly increased flexibility over areas that we can examine. We are better able to follow patients over long periods of time and

across institutional boundaries. Because the LRG was founded by patients and caregivers, we are in touch with the real life issues that

## Our History

A small group of patients on the original trial for Gleevec began comparing notes via an email community. From their reports a patient tracking system was born. Over a period of a couple of years the registry grew to include more than 900 patients.

come up on a daily basis. This connection allows us to track treatments and issues that are of concern to GIST patients today.

Perhaps more importantly, by moving beyond the role of patient advocates to become patient scientists, we are changing the medical research environment. We can design and conduct our own

studies. We are claiming a voice at the decision making table and influencing what research is being done and how it is being conducted.

A sample screen shot of the LRG GIST Patient Registry. Please note that this is not a real patient.

# Our Research Publications

## October 2001

### Gleevec side effect study:

Although not a unique topic, the LRG looked beyond what was being studied in clinical trials. The LRG developed a new scale for evaluating the severity of side effects that focused on quality of life from a patient's point of view as opposed to the toxicity ratings established by the National Cancer Institute. It collected information on the care available to study participants at the various clinical trial sites. A method by which cancer patients could effectively serve as their own control group was designed.

[www.liferaftgroup.org/news\\_sci\\_articles/patients\\_report\\_fatigue\\_SE.html](http://www.liferaftgroup.org/news_sci_articles/patients_report_fatigue_SE.html)

## November 2004

### Gleevec Dosage Study:

presented at the Connective Tissue Oncology Society

LRG data showed that higher doses of Gleevec are related to lower rates of resistance. This was consistent with early results of a larger European study. We suggested a

treatment paradigm that included beginning with a lower dose of Gleevec to minimize side effects and gradually increasing the dosage to at least 600mg to maximize treatment response.

More importantly, this study looked at the actual dose that patients took as opposed to the initially prescribed dose. Most clinical trials assign patients to a treatment dose level; this is the starting dose. Even if patients' doses are reduced, they are included in the original assigned starting dose when calculations are performed.

The LRG compared the starting dose to the actual dose and found that there was a significant difference in the development of resistance.

[www.liferaftgroup.org/news\\_sci\\_articles/starting%20vs%20actual%20dose.html](http://www.liferaftgroup.org/news_sci_articles/starting%20vs%20actual%20dose.html)

## June 2007 & October 2007 Pediatric/Young Adult Summary:

LRG data on patients diagnosed at 30 or less years of age was summarized. This was pre-

sented to a group of experts that met in Seattle in November 2007.

[www.liferaftgroup.org/pediatric\\_gist/gist\\_pediatric\\_data.html](http://www.liferaftgroup.org/pediatric_gist/gist_pediatric_data.html)

## March 2008

### The effect of imatinib dose upon the survival of metastatic GIST patients:

Previous studies of low and high dose levels of Gleevec using starting dose analysis have shown a small statistical benefit in progression free survival (PFS) but no benefit in overall survival (OS). We investigated whether actual dose analysis produced an increased survival benefit for patients showing a clear response to imatinib therapy. A statistically significant benefit was found for PFS and OS.

In addition, higher mortality rates were found for those patients that progressed early on in the study. These results suggest that increasing imatinib doses to at least 600

mg prior to progression leads to improved patient survival.

[www.liferaftgroup.org/docs/newsletters/March2008nwsltr.pdf](http://www.liferaftgroup.org/docs/newsletters/March2008nwsltr.pdf)

## How you can help

You can help by participating in the LRG Registry. If you are not yet a member of the LRG, visit our website to join. The application collects much of the basic data that we need. If you are already a member, fill out the medical update form on our website following each scan or treatment change.

# Recognition

## Magic Cancer Bullet, 2003

Daniel Vasella, M.D., CEO of Novartis

Robert Slater

"The Life Raft Group that Norman helped to start (and has since become the leader of) has provided various people, patients, doctors, investigators, with a unique kind of data bank that cannot be replicated anywhere".

## Wired Magazine, September 2001:

Sara Solovitch

"Cyberspace has spawned a powerful breed of advocates. Consider the case of Gleevec. Members of an internet group spread the word about Gleevec, bringing scores of patients into new clinical trials. Then they went one step further, creating a group called Life Raft, where participants in one trial could share information about the drug's efficacy, its side effects and their interactions with doctors. Conservative clinical oncologists cringed. Life Raft represented a major break with medical precedence."

## July-August, 2001 LRG Newsletter:

Charles Blanke, M.D., Director, GI Oncology Program, OHSU Oregon Cancer Institute

"What are the implications of patient-generated data?

This is powerful and compelling stuff! I remain incredibly impressed by the data-coordinating abilities of the Life Raft personnel. I see the major purpose of this sort of data as hypothesis-generating. Unfortunately, it cannot be free of bias and thus cannot stand by itself, but it certainly can point investigators and the Company in the right direction and let us know what we need to be looking at more closely. Thus, its importance cannot be overstated."