



## **Life Raft Group** *Ensuring that no one has to face GIST alone!*

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### **FOR IMMEDIATE RELEASE**

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## **LIFE RAFT GROUP ANNOUNCES GIST COLLABORATIVE TISSUE BANK INITIATIVE**

**Innovative project will allow GIST researchers worldwide to access GIST tissue linked to patient-provided clinical histories**

**Wayne, N.J.**— Life Raft Group (LRG), the pre-eminent patient-based organization dedicated to finding a cure for a deadly cancer called gastrointestinal stromal tumors (GIST), today announced the launch of the **GIST Collaborative Tissue Bank**, a partnership between twelve internationally-renowned GIST researchers and the Life Raft Group, whose Patient Registry houses the world's largest patient-provided GIST clinical database. The cutting-edge project will promote sharing of tissue as well as the data generated from the studies of this tissue. The Stanford University School of Medicine will serve as the tissue repository and data host through its Tissue Microarray website (<http://tma.stanford.edu>).

“Partnering with a patient-based registry which has the potential to mobilize thousands of GIST patients on a worldwide scale to contribute not only their tissue, but also in-depth clinical histories, creates enormous potential for major research breakthroughs” said Dr. Matt van de Rijn, professor of pathology at Stanford and lead researcher on the tissue bank project. “Scientists studying tissue usually have limited information about that patient’s clinical history. Being able to examine tissue in one patient over time and compare that to tissues from other patients with similar disease progression patterns will significantly accelerate our understanding of the underlying mechanisms of GIST.”

Other members of the GIST Collaborative Tissue Bank include: Dr. Cristina Antonescu and Dr. Peter Besmer, Memorial Sloan Kettering Cancer Center; Dr. Sebastian Bauer, West German Cancer Center, Germany; Dr. Chris Corless & Dr. Mike Heinrich, Oregon Health & Science University; Dr. Maria Debiec-Rychter, Catholic University of Leuven, Belgium; Dr. Anette Duensing, University of Pittsburgh Cancer Center; Dr. Jonathan Fletcher, Brigham & Women’s Hospital; Dr. Brian Rubin, The Cleveland Clinic; Dr. Constantine Stratakis, National Institutes of Health, Pediatric & Wildtype GIST Clinic and Dr. Rob West, Stanford University School of Medicine.

Each year, 5,000-10,000 people in the U.S. are diagnosed with GIST, a rare and often deadly sarcoma, for which there is no known cure. Over the last ten years, with the advent of oral targeted chemotherapies such as Gleevec™ and Sutent™, patients can often remain stable for years. However, the majority of patients become resistant to treatment over time, making the need for more assertive research much more pressing.

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**For more information:**  
[http://www.liferaftgroup.org/research\\_tissue.html](http://www.liferaftgroup.org/research_tissue.html)



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“The LRG has aggressively funded GIST research for the last three years but as a patient-driven organization we knew that we could play an even greater role in the search for a cure” said Jerry Cudzil LRG, Board President “Now patients can donate their tissue and medical histories becoming active participants in the research process which is very empowering for patients and family dealing with a life-threatening disease.”

Since its founding, the LRG has maintained an extensive GIST patient registry, which cuts across institutional and geographical boundaries, by collecting medical updates directly from GIST patients. Today, with over 1,100 GIST patient clinical histories, it is the largest database of its kind. In 2006, LRG began funding a team of leading GIST experts who have been working together collaboratively and cooperatively through its **Pathway to a Cure** research effort. As with other rare diseases, one of the most urgent research needs identified by the team was for GIST tissue. Working together, the LRG and researchers came up with a unique model that could not only deliver tissue but could also provide the even more elusive puzzle piece: comprehensive GIST clinical histories linked to tissue. The key was involving patients who could gain accesses to their tissue samples in the form of paraffin tissue blocks, which are archived in the hospitals where surgery took place. Patients and family members will have their paraffin tissue blocks from surgical procedures (sometimes conducted over many years at different facilities) sent to the LRG Patient Registry. The LRG, in turn will forward the tissue and clinical histories (de-identified to comply with research privacy regulations) to Stanford University, the tissue repository and data host. With this novel system, researchers will now be able to study annotated GIST tissue in ways that have never been possible before. For example, scientists will be able to compare primary tumor tissue and metastasized tumor tissue from individual patients and then look for genetic similarities in other patients.

“Being able to do something to help find a cure for my disease gives me hope that a cure will be found faster” says Anne Pacifico, one of the first GIST patients to donate tissue to the project, “I’d much rather that my tissue is put to good use by scientists than just sit in a file. Research is our best hope and I want to be part of it.”

**More about the Life Raft Group (<http://www.liferaftgroup.org/newsroom.html>):**

*The LRG is committed to finding a cure for GIST and is the largest private funder of GIST research. LRG also serves as a resource for GIST patients through its Information and Support, Patient Outreach and Assistance and Advocacy program areas. Each year the LRG reaches a network of over 60,000 people in over 50 countries through its online community, newsletters, websites, webcasts, supports groups and educational materials. Until a cure is found, the LRG aims to reach and educate as many patients and doctors as possible to create a world where all GIST patients are treated with expert care.*

**More about GIST:**

*GISTs belong to a group of rare cancers called soft tissue sarcomas that can occur in connective tissues, bones, muscles, fat, nerves, blood vessels, and cartilage. About 40-70% of GISTs originate in the stomach, 20-40% in the small intestine, and 5-15% in the colon and rectum. In 2000 scientists discovered a way to properly diagnose GISTs by testing for the expression of the C-Kit protein. That same year the introduction of Gleevec® (imatinib mesylate), a molecularly targeted drug specific to the C-Kit protein, resulted in an 85% response by GIST patients who had previously had few effective treatment options. With patients now developing resistance to Gleevec® LRG is racing against the drug resistance clock to find new treatments to save their lives.*

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