

## GIST Collaborative Tissue Bank

### Why a GIST Collaborative Tissue Bank?

Due to the rarity of GIST, one of the most urgent research needs is for tissue samples. The GIST Collaborative Tissue Bank brings together GIST researchers and GIST patients in a unique partnership. For patients, it's an opportunity to reach the world's leading GIST research scientists with one tissue donation, maximizing both tissue and precious research time. For researchers, it's an opportunity to access tissue linked to GIST clinical histories and to share valuable tissue and critical data.

### How is the GIST Collaborative Tissue Bank different?

The Life Raft Group (LRG), which maintains the largest patient-provided clinical database in the world, has joined with cancer researchers to create a one-of-a-kind tissue bank, where patient tissue is linked to their GIST clinical histories. The Collaborative Tissue Bank has been designed to:

- Allow multiple researchers to share rare tissue.
- Maintain patient privacy: identifying information will be removed from tissue samples and patient clinical histories.
- Create a system for researchers to share data thereby speeding up communication of vital results and reducing duplication of efforts.

### How did the Collaborative Tissue Bank project develop?

#### Background:

The LRG's Pathway to a Cure began in 2005 to find ways to counteract the Gleevec resistance, which occurs in many patients within a few years of treatment. With the traditional research and drug development process taking up to 15 years to produce new therapies, we decided to take action. To accelerate the research process, the LRG forged a partnership with the research community, creating a collaborative and cooperative research effort. Our research goals were clear from the beginning: First, turning GIST from a life-threatening disease into a chronic condition managed with medication; and second, finding a cure for GIST.

#### Research Dilemma:

Due to the rarity of GIST, one of the most urgent research needs is for tissue samples. Without samples, scientists cannot conduct basic experiments to unlock the mysteries of GIST biology and to test and find new treatments. From the beginning, the LRG recognized this need and funded both adult and pediatric tissue banks. However, even when researchers were able to acquire tissue, patient privacy regulations prevented them from having complete clinical histories of these patients and from sharing information and results with



### Research Dilemma cont'd:

other researchers. This is complicated by the fact that patients often see multiple doctors at multiple institutions during the course of their treatment so that often no one physician or institution has a complete clinical history of that patient. Our research team came to us to see if we could find a way to overcome these research obstacles and provide them with the missing pieces of the research puzzle: GIST tissue linked to clinical histories.

### The Solution:

Since its inception, we have been maintaining an extensive GIST patient registry that cuts across institutional and geographical boundaries by collecting information from patients. Today, with more than 1,800 GIST patient clinical histories, it is the largest database of its kind in the world. Working together with our research team, we devised a system to integrate this patient-based registry with our lab-based research efforts. The key is patient submission of paraffin tissue blocks. These tissue samples are on file in the pathology labs where patients had their surgeries and they remain archived by law. Tissues are typically required to be held for five to six years, but these requirements vary by state. By having patients send their paraffin tissue blocks to LRG, who in turn will send it to researchers (without personal information, to comply with research privacy regulation), who will have GIST tissue linked to patient clinical histories for the very first time. This unique project allows researchers to analyze tissues 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. Finally, GIST Collaborative Tissue Bank members are working to develop a shared data system so that results of this and other projects can be shared, creating a truly integrated research effort.

**Because of this unique ability to combine rich clinical data with patient tissue, the LRG was selected to collaborate in a unique research project with New York Presbyterian/Columbia University Medical Center.**

**Learn more about our GIST Tissue Bank:**

<http://bit.ly/TissueBankLRG>



155 US Highway 46, Suite 202  
Wayne, NJ 07470

p: 973-837-9092

f: 973-837-9095

[www.liferaftgroup.org](http://www.liferaftgroup.org)

[liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)