The Life Raft Group Announces Collaboration with OHSU on GIST Tissue Bank

Building on LRG’s 20-Year history maintaining a tissue bank, this unique partnership provides new opportunities.

The Life Raft Group (LRG) recently entered into a collaboration with Oregon Health & Science University (OHSU) to store and distribute research tissue to help unlock the mysteries of GIST biology and support research leading to new treatments. Due to the rarity of GIST, one of the most urgent research needs is for tissue samples. Without samples, researchers cannot conduct basic investigations into the complexity of GIST, nor can they develop new theories that may lead to potential treatments. Tissue is the “gold coin” in GIST research.

The project is unique in that the de-identified tissue is linked to detailed clinical and molecular histories curated by the LRG. The LRG has a unique patient registry with over 2,000 members. The combination of the LRG GIST Patient Registry and the GIST Collaborative Tissue Bank offers a rich source of material for researchers and clinicians striving to unlock the mysteries of this rare disease.

Building upon the precedent-setting collaboration by the Life Raft Group and Stanford University in 2009, the GIST Collaborative Tissue Bank tissue was originally stored at Stanford University, and was designed to provide critical access to researchers. Tissue has provided valuable insights for research projects around the globe. The new partnership with OHSU takes the concept of a patient-driven tissue bank to the next level.

The tissue will now be housed at the OHSU Knight BioLibrary, a research and repository facility within the OHSU Knight Cancer Institute. This facility is a College of American Pathology (CAP) accredited biorepository. All samples will be de-identified, and HIPAA regulations will be followed to assure confidentiality.

This collaboration is an important example of the vital role patient advocacy groups and academic institutions play in bridging the gap between researchers and motivated patient populations who want to share their clinical histories and tissue to create new treatments and better outcomes. The GIST Collaborative Tissue Bank has already provided tissue for cutting-edge research projects, including one at Columbia Presbyterian Medical Center.

Researchers requesting tissue should contact
Denisse Montoya, Director of GIST Patient Registry:
dmontoya@liferaftgroup.org

Patients wishing to participate in the research by donating tissue will need to join the LRG’s GIST Patient Registry and sign our Tissue Bank consent forms. The patient will need mutational testing, and their doctor will need to sign a requisition form. The LRG’s Patient Registry staff will then reach out to the patient’s hospital pathology department to retrieve tissue blocks. Once the blocks arrive at the LRG, the staff will de-identify the tissue and input all information into the Tissue Bank database. All de-identified blocks will then be forwarded to OHSU for storage or testing.

To learn more about the LRG’s GIST Collaborative Tissue Bank, visit: https://liferaftgroup.org/tissue-bank/
Interested in Submitting an Article to LRG Science?

LRG Science is based on a foundation of Real World Evidence and Real World Data collected from: The LRG GIST Patient Registry, Global Surveillance Team, and our collaborative efforts such as the Pediatric & SDH-Deficient GIST Consortium.

We welcome content from other sources of Real World Evidence, and invite submissions of articles, editorials, case studies or breaking news for future issues, most especially, although not limited to gastrointestinal stromal tumor, SDH-deficiency and sarcoma.

To inquire about authoring an LRG SCIENCE article, providing commentary on an article, or to subscribe to our LRG SCIENCE mailing list, please contact Mary Garland, Director of Communications at mgarland@liferaftgroup.org.