Chordoma Foundation Biobank

the starting point for chordoma research

Access to chordoma tissue is the biggest obstacle standing in the way of advancing chordoma research. To solve this problem, the Chordoma Foundation Biobank will proactively collect, analyze, and distribute high quality tissue and associated data to and from hospitals and labs across the world.

Why a Biobank?

The first step in the path towards curing any cancer is understanding the molecular abnormalities that cause it. To do this, scientists use sophisticated technologies – many developed just in the past 5 years - to study the molecules, such as DNA, RNA and proteins, inside tumor cells. Therefore the tumor tissue that is removed from cancer patients holds the key to understanding, and ultimately beating, cancer.

*In March 2009, **Time Magazine** placed biobanking on its list of "10 Ideas Changing the World," highlighting the growing realization that the future success of medical research, especially for cancer, hinges on increasing the supply of high quality biospecimens.*

It is therefore startling that most tumors are discarded after surgery, and those that are saved are usually not stored in a way that maximizes their value for research. In fact, according to the National Cancer Institute, 70% of cancer researchers find it difficult to obtain the quantity of biospecimens, and 80% find it difficult to get the quality of biospecimens needed to do their research. Due to its rarity, this problem is greatly magnified for chordoma, meaning that almost all would-be chordoma researchers are hamstrung by scarcity of tissue. Simply put, finding a cure requires making chordoma tissue available to researchers.

Patients Are Part of the Cure

The Chordoma Foundation Biobank will give patients an opportunity to actively participate in the search for a cure by contributing tumor, blood, DNA, and clinical information about their disease.

Because the sort of high-power genomic analyses that have the most potential to jumpstart chordoma research require pristine tissue that is quickly frozen, the Chordoma Foundation will work with hospitals, physicians and patients to make sure that high quality tissue is obtained properly and quickly shipped to the biobank.

A Unique Resource

All tumors that are collected will be divided to the extent possible so that the same tumor can be distributed across multiple labs and used for many different types of analyses. Importantly, unlike most other banks, results generated on each sample that is distributed will be aggregated into a centralized database to allow researchers in different labs to directly compare and reproduce results on the same tissue samples. In addition, the Chordoma Foundation will follow patients over time so that molecular discoveries made on the tumors can be correlated with outcomes in the clinic.

In addition to providing tissue to chordoma researchers, the Biobank will serve a unique role by generating genomic information on each tumor sample, and making this information freely available to the scientific community. This will enable scientists all over the world – even those studying other diseases – to search for clues about the causes, and potential treatments, of chordoma.

Finally, by obtaining fresh (live) tumor cells the Biobank will feed the development of much-needed research tools such as cell lines and animal models, which are essential for developing and testing new treatments for chordoma.