



FREQUENTLY ASKED QUESTIONS

Does it matter when I contact the Chordoma Foundation?

Yes. The sooner you contact us, the more likely we will be able to obtain your tissue. If you contact us before surgery we can work with your hospital to ensure that your tissue is saved in such a way that it is most useful for research. Otherwise, your tissue may not be made available for chordoma research.

Will contributing to the Biobank affect my care?

No. Your safety and health always come first. No additional tissue will be removed surgically as a result of your participation in the Biobank. Only tissue not needed for diagnosis or care (tissue which would otherwise be discarded) will be used for research.

Will I learn about results of research performed on my tissue?

No. Tissue contributed to the Biobank is for research purposes only. Results generated from this tissue are experimental in nature and should not be relied upon for medical care.

What about privacy?

Your privacy is very important to us. To protect your privacy, each tissue sample sent to the Biobank is labeled with a unique identification number and any personal information is removed. Researchers only see these identification numbers so they never know the identity of the patients whose samples they receive.

Does it matter where I have surgery?

We value each sample we receive, and we will make every effort to collect tissue regardless of where you have surgery. However, please be aware that there are some hospitals and situations in which it will not be possible for us to obtain tissue.

PATIENTS HAVE THE POWER TO ADVANCE RESEARCH

Researchers need chordoma tissue to make discoveries that will lead to new treatments and ultimately a cure for chordoma. However, lack of chordoma tissue poses a major challenge to advancing chordoma research. One important way that patients can help overcome this challenge and expedite chordoma research is by donating tissue to the Chordoma Foundation Biobank.

WHAT IS THE BIOBANK?

The Chordoma Foundation (CF) Biobank is a centralized repository of tumor tissue and blood contributed by chordoma patients to help advance research. The CF Biobank protects and preserves these samples and makes them available to qualified researchers interested in studying chordoma. A single sample sent to the Biobank may be divided and shared among several different labs to support multiple research studies. Additionally, the CF Biobank collects clinical information from chordoma patients to enable research into factors that affect treatment and outcomes.

To learn more visit:

www.chordoma.org/biobank

CONTACT US:

877-230-0164

biobank@chordoma.org

HOW TO CONTRIBUTE:

If you have an upcoming surgery:

- Contact us at 877-230-0164 as far in advance as possible. We will make arrangements with the hospital to collect tissue remaining from your procedure that is not needed for your care.
- Tell your surgeon that you want to contribute tissue to the Biobank. Your surgeon can help by encouraging the hospital staff to work with our Biobank team to make sure your tissue is saved and can be used for research.

If you had surgery in the past:

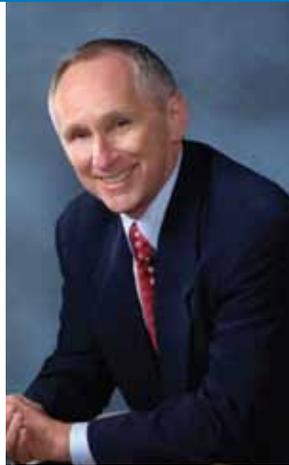
- Tissue from a previous surgery might be stored at the hospital where you were treated. Let us know when and where you had surgery, and we will attempt to locate and obtain this tissue.

WHY CONTRIBUTE?

Because chordoma is so rare, each tissue sample is very important for research. Chordoma patients have a unique opportunity to help advance chordoma research by contributing to the Biobank.

“ I am happy to be able to donate my tissue to the Chordoma Foundation Biobank because I know how important it is for researchers in order to develop new treatments for chordoma. ”

-STEVE KANTER, MD
Sacral chordoma survivor



“ The Chordoma Foundation biobank provides a critical resource to the research community. Contributing tissue to the Biobank is a good way for patients to make a difference in chordoma research. ”

-DERIC PARK, MD
Neuro-oncologist & chordoma researcher,
University of Virginia



P.O. Box 2127
Durham, NC 27702

CHORDOMA FOUNDATION BIOBANK



TUMOR TISSUE IS CRITICAL FOR RESEARCH NEEDED TO DEVELOP NEW TREATMENTS.

LEARN HOW YOU CAN HELP BY DONATING TISSUE.



Giving patients the power to advance research.

