

INFORMATION AND ASSENT FORM

Ages 7–17

Project Title: The Chordoma Foundation Biobank: A Collection of Biospecimens and Clinical Data to Facilitate Research
Project #: 001
Sponsor: Chordoma Foundation
Principal Investigator: Patricia Cogswell
Chordoma Foundation
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WHAT IS THIS PROJECT ABOUT?

The Chordoma Foundation is a group of people trying to help scientists make medicines and find a cure for chordoma and other diseases. The Chordoma Foundation wants to collect samples that will help scientists learn what makes people sick and how to make them better. This collection of samples is called a “biobank”. The Chordoma Foundation wants to know if you will give the biobank samples or information to help the scientists. What the scientists do is called “research”.

DO I HAVE TO BE IN THIS PROJECT?

You do not have to be in the project if you don’t want to.

Even if you say you want to be in the project now, you can change your mind later. If you change your mind later, tell your mom or dad so they can tell the Chordoma Foundation.

You can ask the project staff questions before you make up your mind. You can also talk to your mom or dad and ask to read the information the project staff gives them.

HOW LONG WILL I BE IN THE PROJECT?

It should take a small amount of time (less than one hour) to learn about you and to collect some blood or spit if you want to donate that. Samples that you give to the biobank may be used right away or could be used later. You can decide if you want your doctor to give the biobank samples from your care that happened in the past or care that will happen now or in the future. The project staff may contact you later to see how you are doing or to tell you about other projects you might be able to join.

WHAT WILL HAPPEN TO ME IN THIS PROJECT?

Your doctor will take care of you normally. If you have a test or an operation, the doctor will give samples from your body such as blood, tissue, or other fluids to the biobank after the doctor is done using them. You can also let a nurse take a sample of your blood with a needle to give to the biobank. You can also choose to spit into a cup or swab the inside of your cheek to give that sample to the biobank. A project staff member will ask you or your mom or dad questions about your health and your doctor may share information about your care that could help the scientists. The scientists will not know who you are. **You can choose to do these things you want to do or you can say you do not want to be in the project.**

Some of these things may have already been done to you, or samples from your body may have been taken before. If so, all you and your parents have to do is say the project staff can use your samples already taken.

Some of the testing done on your samples will include genetic testing. Genes are things in your body that make you different from anyone else. Genes are often called “DNA.” Some genes control things like the color of your hair or eyes. Other genes might make you more likely to get certain diseases like chordoma. **You do not have to allow this genetics testing if you don’t want to. However, if you want to be in the project, you have to have this genetics testing, too.**

WILL BEING IN THIS PROJECT HELP ME?

Being in this project may not help you, but it may help people in the future. You may never know about the research that scientists do with your samples and information.

CAN ANYTHING BAD HAPPEN TO ME IN THIS PROJECT?

If you agree to give blood, the nurse will take your blood with a needle or your doctor may take some extra blood during any test or operation you have. Some problems you might have from this are:

- pain
- bruising
- feeling dizzy
- infection at the place where the needle went into your arm.

You might not want the scientists to know your name. There is a very small chance that someone doing research might figure out which samples came from you.

What researchers find out about your genes is private. But if the results of the gene tests got into the wrong hands, some of your privacy may be lost. Genes can tell a lot about you and your health. The Chordoma Foundation will try to make sure that scientists who find out about your genes will not know your name.

WHO CAN I TALK TO ABOUT THE PROJECT?

You can ask questions about the project any time. You can call the Principal Investigator, the person in charge of the project any time. The Principal Investigator’s phone number is on the first page.

If you want to ask questions about what it means to be in a biobank project, you or your mom or dad can call Quorum Review at 1-888-776-9115 (toll free).

DO YOU WANT TO BE IN THIS BIOBANK PROJECT?

Please sign below if you want to be in this project, but remember: You don’t have to be in this project if you don’t want to.

Name of Child (Print)

Date of Birth

Signature of Child

Date

I attest that the participant had enough time to consider this information, had an opportunity to ask questions, and voluntarily agreed to be in this project.

Name of Person Explaining Assent (Print)

Signature of Person Explaining Assent

Date