

COLLAGEN DIAGNOSTIC LABORATORY (CDL) REPOSITORY UNIVERSITY OF WASHINGTON, SCHOOL OF MEDICINE

SEATTLE, WA 98195-7470

Assent Form (ages 7 to 12): **Repository for Heritable Disorders of Connective Tissue**

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Researcher's Statement

We are asking you to be in a research study. The purpose of this paper is to give you the information you will need to help you decide whether or not to be a part of the study. You may want to read this form to yourself or, if it is easier, to have someone read it to you. Please ask any questions that come up when you are reading the form: ask about the reason for the research study, ask about what you have to do as part of the study or anything else that isn't clear. When all of your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent". We will give your parents a copy of this form to keep at home.

PURPOSE AND BENEFITS

Today, you are having a skin test or a blood test to figure out if you have a genetic condition called osteogenesis imperfecta/ Ehlers Danlos syndrome/ Marfan syndrome/ "genetic connective tissue disorder"/ _____ (other). After we do a lab test to see if you have this disorder, we would like to freeze and store the cells from your skin or blood. Later, we may want to use the samples to understand more about the medical problem that you have. We also want to read a report from your doctor about any health problems that you have had. This is a science study and we are asking you if it's okay to keep your cells and read about you.

PROCEDURES

After your lab test is done, we will take the cells that we studied and put them in a small tube and store them in a freezer. If it was a blood sample that was taken, we will take the DNA from the blood and store that in a freezer. When we want to learn more about a medical disorder, we will thaw the cells or DNA and study them. The medical information about you will be copied to a computer file and stored. Later, we will compare information about you to information about other people with the same disorder.

RISKS, STRESS, AND DISCOMFORT

There will be no discomfort or pain to you from agreeing to participate in this study.

OTHER INFORMATION

We won't tell anyone you took part in this study. You do not have to take part in this study if you don't want to. No one will be mad at you. If you decide to take part in the study and then change your mind, that's okay too. One of your parents or your doctor can tell us if you change your mind.

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HUMAN SUBJECTS DIVISION

Signature of Investigator

Printed Name

Date

Subject's statement

This science study has been explained to me. I agree to take part in the study. I have had a chance to ask questions. If I have more questions I know I can ask the doctor.

Signature of Subject

Printed Name

Date

Copies to: Subject
 Investigator's file

APPROVED

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