

RESEARCH REPOSITORY (RR) FOR HERITABLE DISORDERS OF BONE BLOOD VESSELS
AND SKIN

UNIVERSITY OF WASHINGTON, SCHOOL OF MEDICINE, DEPARTMENT OF PATHOLOGY
SEATTLE, WA 98195-7470

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RR Child Assent Form (Age 7 to 12)

SEP 22 2015

AUG 29 2013

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SEP 18 2014

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RESEARCHER'S STATEMENT

We are asking you to be in a science study. This paper will help you understand what the study is about. Then you can decide if you want to be a part of the study. You can read this paper yourself or you can have someone read it to you. Please ask us any questions that you have when you are reading the paper. You can ask any questions that you have about the study. You can ask about the reason for the science study or about what you would do to be in the study. When we have answered all of your questions then you can decide if you want to be in the study or not. We will give your parents a copy of this form to keep at home.

PURPOSE OF THE STUDY

Our lab studies problems with joints, skin, bones, arteries, and veins. We want to find out what makes problems like these come up in families. Because you have a problem like this we are interested in studying you and your family. We want to collect, save and study the cells from your skin or blood. 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 your health.

PROCEDURES

To be in the study, we need to get saliva (spit), blood or a sample of your skin or both.

- Saliva sample: To get a sample of your spit, we give your parents a "spit kit" with directions about how to collect the sample in a tube.
- Blood draw: To get a sample of your blood, we will take about 3 teaspoons of blood from a vein in your arm using a needle.
- Skin biopsy: To get a sample of your skin, we have to take a small piece off. We use a small tool that will take a little circle of skin for the sample. The sample is very small. It is about the size of a grain of rice or a

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small green pea. Before we take the sample we will make your skin numb so it won't hurt. We will do that with medicine that is put into your skin through a small needle.

We will keep the saliva, blood and skin samples at our Laboratory at the University of Washington.

When your sample is sent to us your doctor will also give us the report about your health. It might also help us to look at your health reports from another doctor or hospital. If we want to do that we will ask you first and give you another paper to sign if you agree

We would also like to send some basic facts about your health to other people who study these types of problems. The facts will be put in a computer with facts from other families. This will help us learn more about diseases that run in families. If you agree to let us send the information, we will not tell them your name.

BENEFITS OF THE STUDY

What we learn from studying your health and your cells may help other people with the same types of problems. What we learn may help you or your family or it may not.

RISKS, STRESS, AND DISCOMFORT

Having blood drawn might hurt a little when the needle is pushed into the skin, like being poked with a pin. If a piece of your skin is taken, the needle used to put numbing medicine in your arm might also hurt. Once the spot is numb, you will not feel it when the piece of skin is taken.

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.

Signature of Investigator	Printed Name	Date
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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
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