

**INFORMATION SHEET FOR CHILDREN AND ADOLESCENTS
(Subjects Ages 16-17)**

TITLE: Joint Health Study

PROTOCOL NO.: None
WIRB® Protocol #20172413

SPONSOR: Bloodworks Northwest

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Why should I be in the study?

We are doing a research study. We want to learn more about both the factor products you take for your hemophilia and if ultrasound images can show earlier signs of joint damage compared to x-rays and MRIs.

What do I have to do?

You can say yes and join this study. Your doctor would like to collect some information about your health from your medical record in order to see if you will qualify for this study. Your doctor or nurse might ask you a few questions about your health. You do not have to answer any questions you do not want to. If you join the study, you will come to clinic at least four times

over three years. We will ask you to complete some questionnaires and assessments; take your blood; and take images of your knees, ankles, and elbows with an ultrasound machine. If you are one of the first ten participants in this study, we will also take x-ray and MRI images of your target joint and the joint on the opposite side.

Will it hurt?

The gel for the ultrasound may feel sticky, but the test should not cause any discomfort or pain.

The x-rays should not cause any discomfort or pain, but there is some minimal exposure to radiation.

The MRIs should not cause any discomfort or pain, but if you have metal in your body you won't be able to have MRIs. The MRI machine makes loud banging noises and you will lie in small enclosed area which may feel scary.

It may feel like a pinch when you give blood. It will hurt for a minute. Sometimes the place where the needle went in can be sore for a while or you might have a bruise for a few days.

How will it help?

This study may help you by getting images of your joints so we can compare your current images to future images to determine if there have been changes over time. The things we learn from this study might help people with hemophilia.

Do I have to be in this study?

Your mother/father said it would be ok for you to participate in this research project. If you do not want to be a part of this research project, you will still get the same care that you have been getting. If you don't want to be in this study, that is okay. If you want to be in the study, you can change your mind later if you want to stop.

Can I ask questions?

You may ask us any questions now that you want. If you think of a question, concern or complaint later on or if at any time you think you have had a research-related injury, you can ask or tell your parent. Your parent can call us to ask a question or tell us of any research-related injuries too.