

Children's Hospital Boston

Name of research study: Molecular Analysis of Skeletal Disease

Person in charge: Dr. Matthew L. Warman

PLEASE DO NOT PLACE IN MEDICAL RECORD

RESEARCH ASSENT FORM

Your Name:

Today's Date

Your Date of Birth:

Your Age:

The reason we asked you to be part of this study:

We have spoken to your parents and they said that it would be ok to ask you if you wanted to be part of a research study. A research study is a way of finding out new information. We know that you or some of your family members have problems with their bones or joints. Doctors call these types of bone problems Skeletal Diseases. Skeletal diseases can affect how tall you grow, whether your joints or bones hurt when you play, and whether there are some activities that you should avoid. This study will try to figure out what genes caused the bone or joint problems in your family and may even figure out why they do. Our goal is to find better ways of helping children and adults who have bone and joint problems.

This study has two parts. The first part of the study involves drawing blood from you and all of your family members who say it's ok. We will draw blood from a vein in your arm or leg one or possibly two times. You will feel a pinch when we use the needle to get the blood. You might have a black and blue spot where the needle went into the vein after the blood is taken. The black and blue spot will go away within one or two weeks. We may ask you to give some of your cheek cells by swabbing the inside of your mouth with a Q-tip. This does not hurt.

The second part of the study involves asking you questions about your bones and joints and other health problems you may have.

We do not know whether this study will help you. With this study, we hope to learn about the gene that causes your type of bone and joint problems. If we know and understand the gene, then we might be able to figure out in the future how to help people who have the same type of bone and joint problems.

You do not have to be in this study. No one will be upset if you don't want to be in this study. If you don't want to be in this study, you just have to tell us. It's up to you. We will keep all the information from this study locked up so that no one except for the doctors and people doing the study will see it.

| Please put a check by the YES o | NO to tell us if you want to be in any part of this study: | |
|---|--|--|
| Is it ok for the doctors to draw yo | ur blood or get a cheek swab from you? | |
| YES | NO | |
| Is it ok for the doctors to ask you YES | questions about your bones, joints and health problems? | |



RESEARCH ASSENT FORM

You can change your mind and stop being part of this study at any time. Even if you write your name on this paper, you can say no later. All you have to do is tell a parent or the doctor. If you have any questions about this study, you can ask a parent or the doctor.

| pelow: |
|----------|
| |
| _Witness |
| |
| - |

This section to be modified by the Clinical Investigation Office only.

Activation date: **September 10, 2007** Expiration date: **September 9,**

2008

Protocol #: 06-10-0440