

ASSENT TO PARTICIPATE IN RESEARCH

The Skeletal Dysplasia Registry Genetics and Pathogenesis of Skeletal Disorders

1. My name is _____.
2. Deborah Krakow, MD and Daniel H. Cohn, PhD are asking you to take part in a research study because we are trying to learn more about your skeleton or bones.
3. If you agree to be in this study we will look at pictures of your skeleton using something called an xray. We will also ask you to allow us to get blood from your arm or spit into a cup.
4. Getting blood from your arm does hurt for a few seconds when the needle goes in. Spitting into a cup many times can make your mouth feel dry.
5. We may find out why your skeleton or bones are different. This may help your family and your doctors take care of you.
6. Please talk this over with your parents before you decide whether or not to participate. We will also ask your parents to give their permission for you to take part in this study. But even if your parents say “yes” you can still decide not to do this.
7. If you don’t want to be in this study, you don’t have to participate. Remember, being in this study is up to you and no one will be upset if you don’t want to participate or even if you change your mind later and want to stop.
8. You can ask any questions that you have about the study. If you have a question later that you didn’t think of now, you can call me at (310) 825-8998, or ask me next time.
9. Signing your name at the bottom means that you agree to be in this study. You and your parents will be given a copy of this form after you have signed it.

Signature of Subject

Date

Print Name