# UNIVERSITY OF CALIFORNIA, DAVIS
# PARTICIPATION OF MINORS IN RESEARCH

## Who are we and why are we meeting with you?

I am Dr. Simeon Boyd and I work at the University of California, Davis in the Section of Genetics of the Department of Pediatrics. We want to tell you about a study that involves children like yourself. We want to see if you would like to participate in this study.

## Why are we doing this study?

We are studying why people are born with problems with the bones of the head. People with those problems may join this research study. We hope to find what causes these problems so we can help other children who have the same problem.

## What will happen to you if you are in the study?

If you join this study, we will take a small amount of blood from your arm. If you need to have a surgery, we may take a bit of skin, bone, and/or muscle that otherwise will be thrown away. Your mom or dad will be with you when we obtain blood. We will then study your blood or skin, bone, and/or muscle.

If for some reason we can not draw blood or if you prefer not to have the needle stick we can collect some saliva from your mouth by making you swish and spit a mouthwash solution Scope or by touching your cheek with a tiny brush. In this case we will have just a little bit of material to study and we may need to collect more saliva from you in the future.

If you join this study, we will also ask your parents to answer some questions about you and your parent's health in a questionnaire. The questionnaire asks for your and your parent's name, address and other questions. Your entire questionnaire will be shared with our craniosynostosis research collaborators, and used only for craniosynostosis research.

If you join this study, we will also ask your parents to sign a permission form which allows us to use your medical record and medical information, for our research. (This will include a copy of a head CT scan, which will be shared with our research collaborators). We will keep your medical information private, and only shared with our research collaborators in this study.

## Will any part of the study hurt?

If you decide to help us with this study you may have a needle stick to draw the blood. It may hurt a little to have the needle put in your arm, and it may leave a bruise.

## Will you get better if you are in the study?

You will not get better if you are in the study. If you decide not to participate you will receive the same medical care as if you are participating. There are no direct benefits for you, but if you participate we may learn more about your condition and may be able to help other kids with the same problem better in the future.

| **APPROVED by the Institutional Review Board at the University of California, Davis** | |
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| Protocol | Approved |
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## Will your information be shared?

Your information may be placed in the central information place such as the database of genotypes and phenotypes (what the disease looks like) also known as dbGaP or other national repository at United States of America, National Institutes of Health (NIH). Other qualified researchers who obtain proper permission may gain access to your sample and /or data for use in approved research studies that may or may not be related to the present study. Sample and data used through such repositories will be monitored and usage approved by the repositories' administrators.

## Who will know that you are in the study?

Only you, your parents and the researchers of this study will know that.

## Do you have to be in the study?

No, you don't. No one will get angry or upset if you don't want to be in the study. Just tell us. And remember, you can change your mind later if you decide you don't want to be in the study anymore.

## Do you have any questions?

You can ask questions at any time. You can ask now. You can ask later. You can talk to me or you can talk to someone else at any time during the study. Here are the telephone numbers to reach us:

| (PI Name) | (Department) | (Phone Number) |
|---|---|---|
| Dr. Simeon Boyd | Pediatrics | (916) 703-0446 |

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