

**UNIVERSITY OF CALIFORNIA, IRVINE
ASSENT TO BE IN A HUMAN RESEARCH STUDY**

ASSENT FORM FOR RELEASE OF MEDICAL RECORDS

Form 1

CLINICAL GENETICS OF CRANIOSYNOSTOSIS

Participating in this study is totally voluntary. Please read about the study below. Feel free to ask questions about anything that you do not understand before deciding if you want to be in the study. A researcher listed below will be around to answer your questions.

RESEARCH TEAM

Lead Researcher:

Virginia Kimonis, MD
Chief, Division of Genetics and Metabolism
Professor of Pediatrics
Department: Pediatrics
Telephone Number: (714) 456-5792
24 Hour Telephone: (714) 506-2063 (Pager)

Study Locations: UCI ICTS, UCI Medical Center, CHOC

WHY ARE YOU BEING CALLED?

I am Dr. Virginia Kimonis. My study team and I work at the University of California, Irvine in the Division of Genetics of the Department of Pediatrics. I want to tell you about a study that involves children like yourself or your brothers and sisters. I want to see if you would like to participate in this study.

WHY ARE THEY DOING THIS STUDY?

I am studying why people are born with problems with the bones of the head. People with those problems or their brothers and sisters and parents may join this research study. I hope to find what causes these problems so that physicians can help other children who have the same problem.

Approved by IRB on: 04/22/11

HS# 2007-5631

Void After: 04/21/12

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WHAT WILL HAPPEN TO YOU?

There are two parts to this study. This is part one where we call and explain to you that we would like to look at the records that your doctor keeps about you.

Part two will happen after part one. If you decide to be in the study, when you come for the first appointment, everything will be explained to you and you will then need to sign another consent form in person with your parents.

WILL THE STUDY HURT?

This part of the study will not hurt.

WILL YOU GET BETTER IF YOU ARE IN THE STUDY?

You will not get better if you are in the study, but if you participate, the study team may learn more about your condition and may be able to help other kids with the same problem in the future.

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 me. And remember, you can change your mind later if you decide you don't want to be in the study anymore. If you decide not to participate you will receive the same medical care as if you are participating.

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 at any time during the study. Here are the telephone numbers to reach Dr. Virginia Kimonis:

Telephone Number: (714) 456-5792

24 Hour Telephone: (714) 506-2063 (Pager)

Signature of Child

Age

Date

Signature of Researcher

Date

Signature of Witness

Date

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