



Approved February 16, 2010

RESEARCH ASSENT FORM

Protocol Title: Genetic Modifiers of Cystic Fibrosis

Application No.: NA_00035659

Sponsor: National Institutes of Health

Principal Investigator: Garry R. Cutting, M.D.

Date: February 16, 2010

We want to tell you about a research study we are doing. A research study is a way to learn information about something. We would like to find out more information about Cystic Fibrosis.

You are being asked to join the study because you and your brother or sister have cystic fibrosis (CF). Some children in the same family have similar problems with their CF while others have very different CF. This study is trying to understand why people from the same family may be different with their CF.

Families with 2 or more children with CF may join. We think about 1000 families will join the study.

If you say yes to this study, it means that you will let study people from Johns Hopkins look at and copy your medical records. Your family will fill out forms about the family's health and you will fill out a personal form about your health. (Your parent may do this for you, or people from Johns Hopkins will ask you).

Blood will be drawn from you, your brother or sister with CF and your parents. The cells and fluid in your blood will be kept forever. Study people will do tests on your blood and your genes (from the blood). We will match how sick you are with your genes to see if we can find the ones that make you sicker or better than your brother or sister. Between one and two tablespoons of blood will be taken from a vein in your arm.

We might ask you later to come to Johns Hopkins for more tests. You do not have to agree to this, even if you have already joined this part of this study.

The blood drawing may hurt a little bit and you might get a small bruise afterwards. We will try to get the blood sample at the same time that you have blood tests ordered by your doctor.



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We do not know if you will be helped by being in this study. We may learn something that will help other children with cystic fibrosis some day.

You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind.

Before you say **yes** to being in this study, we will answer any questions you have

If you want to be in this study, please sign your name. You will get a copy of this form to keep for yourself.

(Sign your name here)

(Date)