CHILDREN'S NATIONAL MEDICAL CENTER

Center for Genetic Medicine, Children's Research Institute
111 Michigan Avenue, NW
Washington, DC 20010
(202) 476-6011

ASSENT (AGES 7 through 11) TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

Family Member of Patient with a Leukodystrophy

TITLE OF STUDY: New Diagnostic Approaches In Leukodystrophy

PRINCIPAL INVESTIGATOR: Adeline Vanderver, MD; Department of Neurology

A & B. WHAT IS THE REASON FOR THE STUDY AND WHAT WILL HAPPEN IN THE STUDY?

1. Participating in this research means that you will allow us to study your genes and proteins to help understand why your family member is sick. Genes are the recipes for how our body works. Family members share some of the same genes, but not all. This research will help us understand why your brother or sister is sick, but you are not.

2. Researchers in a laboratory will look at your genes to see if there is a change that can help us understand your family member's health problems.

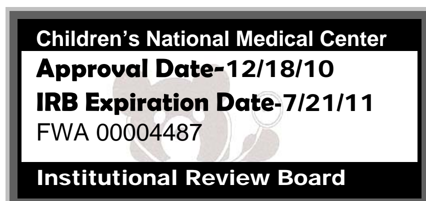
3. Unless we find something in your genes that affects your health, we will not tell you what we learn about your genes.

C. WHAT POSSIBLE UNEXPECTED THINGS COULD HAPPEN?

You may feel upset and sad because your family member is sick, and because the doctors are doing tests to find out what is making him or her have health problems. If you are upset, you should talk to your parents about this and they may bring you to the doctor to talk about your feelings.

D. WHAT POSSIBLE GOOD THINGS COULD HAPPEN?

By having samples from individuals with genetic disorders and their family members, our laboratory has made discoveries about genes and proteins that have added to our understanding of the genetic conditions and may allow treatment in the future. It



may also mean that your doctor gets a specific answer to what is making you have problems with your health.

ASSENT
I understand what the doctor has told me and I want to be in the study.

Printed Name of Participant: ____
Medical Record Number: ____

Signature of Participant: ____

Witness (to signature): ________________________________Date:___________
(may be investigator)

Translator's Signature (if, applicable): ______________________Date:___________
Language: ______________________________________

AFFIDAVIT OF PERSON OBTAINING ASSENT: I certify that I have explained to the above individual(s) the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised.

Printed Name of Individual Obtaining Assent: _________________________________

Title: _______ Signature: ________________________________ Date: __________