

**CHILDREN'S HOSPITAL AND REGIONAL MEDICAL CENTER
and the
UNIVERSITY OF WASHINGTON**

Genetic Analysis of Heart Defects
Michael Bamshad, MD

Children's Hospital and Regional Medical Center
Seattle, Washington
Institutional Review Board

**Assent Form
FORM A**

JAN 02 2008

Genetic Analysis of Congenital Heart Defects

APPROVED

| Name | Position | Department/Division | Telephone |
|------------------------|-------------------------------|--|---------------------|
| Mike Bamshad | Principal Investigator | Pediatrics/Genetics&Development | 206-221-4131 |
| Maggie McMillin | Study Coordinator | | 206-221-3849 |

What is research?

We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things.

Being in research is your choice. You can say Yes or No. Whatever you decide is OK. We will still take good care of you.

Why are we doing this research?

We are looking for genes that cause problems of the heart. Genes are found inside cells. Genes tell the body how to grow and develop. In our research study we want to find genes that tell the heart how to grow and develop. We want to study genes from you and your family members.

We are asking you to be in this research because you have problems with your heart. We want to study your genes and the genes of the people in your family.

What will happen in the research?

If you decide to be in this research study, we will ask to take some of your blood. We want to take about 1 teaspoon of blood **one** time. We will take the genes out of the blood cells and study the genes.

We will ask you, your parents, and your other doctors about your health. We will look at your medical record and collect some health information.

We may also ask to take pictures of your heart using sound waves. This test is called an echocardiogram and it is painless. We may also ask to take a picture called a chest x-ray. This will not hurt. You can choose not to let us take these pictures. You can still be in this research study if you decide not to let us do the echocardiogram or the chest x-ray.

What are the good things that can happen from this research?

What we learn in this research will probably not help you now.

When we finish the research we hope we know more about how genes cause heart defects. This may help other children with heart defects later on.

What are the bad things that can happen from this research?

When your blood is drawn it may hurt and you might get a little bruise on your arm.

What else should you know about the research?

Being in the research is your choice. You can say Yes or No. Either way is OK. Whatever you choose, we will still take good care of you. If you say Yes and change your mind later that is OK. You can stop being in the research at any time. If you want to stop, please tell Dr. Bamshad.

All information gathered about you will be kept privately. We keep all the research records locked in an office. We will put a code number on the blood sample so only the research doctor will know the blood is yours.

Take the time you need to make your choice. Ask us any questions you have. You can ask questions any time.

Signature of investigator obtaining assent _____ *Date* _____

Child's Statement

The researchers have told me about the research. I had a chance to ask questions. I know I can ask questions any time. I want to be in the research.

Signature of child _____ *Date* _____

Signature of parent _____ *Date* _____

*Copies to: Child and Parent
Researchers*