

**Rare Blood Disorder Surveillance Project
INFORMATION SHEET AND ASSENT FORM**

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Nurse Coordinator: **Bonny Marx** **407-8822**

You have a rare blood disease. This means there are certain cells or other things in your blood that are missing and cannot do their job. You have been asked to give some blood to be stored and tested to see why you got this disease and how treatments might hurt you. Your genes will also be studied to look for reasons why people like you get your disease.

What will you have to do?: If you and your parents agree to take part, we will ask you to come to our office. We will ask you to give us some blood (about 1 teaspoon if you are under 5 years old, or 2 teaspoons if you are 5 and older) and some urine (about 2 teaspoons).

Will it help?: Your blood and urine may help us find the problem and will help others with your disease.

Will it hurt?: Taking your blood might hurt a little or cause a bruise where blood was taken. Any information that is found out will be put into your medical records.

Can you quit?: You don't have to take part in the study at all, and you can quit at any time. No one will be mad at you if you decide you don't want to do this, or if you decide to stop part way through. You should tell the doctor or nurse that you want to quit.

Who will know?: No one except your parents and the doctor will know you're taking part in the study unless you want to tell them. Your name and your chart won't be seen by anyone except the doctors and nurses during the study.

Your signature: We would like you to sign this form to show that you agree to take part. Your mom or dad will be asked to sign another form agreeing for you to take part in the study.

Do you have more questions? You can ask your mom or dad about anything you don't understand. You can also talk to Dr. Ritchie or your nurse. Their phone number is 492-3550.

I agree to take part in the study.

<signature of research participant>

<date>

<signature of witness>

<date>

<signature of investigator>

<date>