

## Research Assent Form

Brigham and Women's Hospital  
Dana-Farber Cancer Institute  
Massachusetts General Hospital

Version III.a August 1998  
Pi\_dist9.doc

Imprint Patient ID Number

**Protocol Title:** Molecular Genetic Analysis of Inherited Kidney Dysfunction

**Principal/Overall Investigator:** Martin R. Pollak, MD

**Site-Responsible Investigator(s)/Institution:** BWH

**Description of Subject Population:** Minors from families with inherited kidney dysfunction

We are doctors from Brigham and Women's Hospital. We would like to learn more about kidney disease and what causes this condition in children, adults, and/or their families. Your kidneys are the organs that make urine and remove unwanted products from your blood. Children or adults who have this condition can develop kidney failure and when this happens, the function of the kidneys need to be replaced either by a machine or a new kidney from another person.

We are asking you and other children with kidney disease (or with family members with kidney disease) to take part in a research study. The results of the study will help us understand the causes of kidney disease. We are especially interested in the genes that cause kidney disease. A gene is a set of instructions that tells every part of your body how to develop, grow and perform. Genes are inherited (or transmitted to you) from your parents. It can take a very long time to find a gene that causes a human condition and our laboratory will work on this study for several months or years.

If you agree, we will also ask you for information during a visit to your doctor's office or hospital. You will be asked questions for several minutes regarding your daily activities, about what you eat and drink and how often you urinate. We will ask you some questions about your health. This should take about ten minutes. You might get bored or tired when the doctor is asking you questions. You do not have to answer any of the questions if you do not want to or if they make you feel uncomfortable.

You may be asked to have an abdominal ultrasound which is a picture of your kidneys and other organs. This takes about 20 minutes to do. This study is done without needles, x-rays, or medicines. You will need to lie on a bed and a recorder (called a probe) that is the size of a microphone will be moved across your abdomen. You may feel some pressure as the recorder is moved.

You will be asked for a sample of your urine. This is a simple test that does not hurt.

We will also draw a small amount of blood (not more than 4 teaspoons; less if you are 16 years old or younger) from a vein in your arm. You will feel a pinch when the needle is placed but this will last for a

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**IRB Protocol No.:** 1999P002030

**Sponsor Protocol No.:** N/A

**Consent Form Valid Date:** 05/12/2009

**IRB Amendment No.:** N/A

**Sponsor Amendment No.:** N/A

**IRB Expiration Date:** 04/20/2010

**IRB Amendment Approval Date:** N/A

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very short time. After drawing your blood you may develop a small bruise (black and blue spot) where the needle was put into the vein.

The information collected about you during this study will be kept safely locked up, and nobody will know who you are except the people doing the research. If we write an article about what we learn from the study, we will not use your name.

Before you decide to take part in this study, we will answer any questions you have. You can also talk to your mom or dad, or your doctor. You do not have to be in this study, it is okay to say no. If you decide to be in this study, you can change your mind and stop being part of it at any time.

You will be given a copy of this form to keep for yourself.

If you decide to be in the study, please sign your name below.

\_\_\_\_\_  
Subject's Signature

\_\_\_\_\_  
Date

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