

**UNIVERSITY OF WASHINGTON**  
**CONSENT FORM**  
**NEUROGENETICS LABORATORY REPOSITORY**  
Parents to use for their Minor Child less than 13 years old

**Researchers:**

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**Division of Genetics and Developmental Medicine, Department of Pediatrics, School of Medicine**

**24-hour emergency number: 206-987-2000**, Children's Hospital and Regional Medical Center. Ask the operator to page one of the physicians above or the physician on call for Medical Genetics.

**Researchers' statement:**

We are asking your child to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether or not to have your child participate in the study. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask your child to do, the possible risks and benefits to your child, his/her rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you may decide if you want your child to be in the study or not. This process is called 'informed consent.'

**PURPOSE OF THE STUDY**

We would like to study genetic neurologic diseases now and in the future. Genetic diseases are caused by changes in a person's genetic material (DNA) and may or may not be passed on from parents to their children. We want to create a Neurogenetics Laboratory Repository. A Repository is a collection of blood and tissue samples from people with these diseases that we will use for research. We also want to have a list of patients, with and without neurologic symptoms, who provide samples to the Repository. We know that these disorders are due to changes in your child's DNA, but we do not know what genes cause these disorders. Our studies may take many years to finish. We may never identify the genetic cause of some diseases. If we do identify the cause of a disease, we may be able to develop better tests and treatments in the future.

**STUDY PROCEDURES**

We are asking you to allow us to keep your child's samples and information. This would include your child's DNA sample, cell lines, medical notes, imaging studies, test reports, and pictures.

If you decide to allow your child to take part in this study, samples of his/her DNA and/or permanent cell lines from his/her blood will be stored. We may ask for other samples that are no longer needed for your child's medical care, for example, skin or tissue collected at surgery or autopsy. We will only obtain samples that are going to be thrown away. We will look for genetic differences in samples from affected individuals in the Repository to understand the genetic causes of these disorders. We will link these samples to information we collect from you about your child. This includes your child's address

and phone number, birth date, gender, ethnicity, and diagnosis. We will enter this information into a database. We will ask you to sign a separate form to allow us to look at your child's medical records. We will also ask about details of your family history, but you may choose not to answer any of our questions. All of this information is kept in locked files and computers.

### RISKS, STRESS, OR DISCOMFORT OF THE STUDY

Although federal laws have been passed to prevent discrimination on the basis of genetic differences, allowing your child to take part in this study might make it harder for him/her to get health insurance if the results get into your child's medical record. We will keep all research results separate from your child's medical record.

Rarely, we find unexpected results. For instance, results might show that the man thought to be the father of a child is not the true biological father. We might also find genetic changes that are not related to the disorder being studied. If we find unexpected results, we will NOT tell you unless the results are important for your child's medical care. We will talk to your child's medical provider before giving out any unexpected results.

### ALTERNATIVE TO TAKING PART IN THIS STUDY

You may choose not to have your child's samples and information stored in the Repository. If you refuse, your child's samples will not be kept forever or shared with other researchers. It will not affect your child's clinical care.

### BENEFITS OF THE STUDY

It is unlikely that your child will directly benefit from this study. If we find specific genes that cause a disorder, we may be able to develop better tests and treatments in the future.

### OTHER INFORMATION

Taking part in this study is voluntary. You or your child may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. Even if you decide now that your child's samples can be used for research, you or your child can change your mind later. Just let us know that you do not want us to use your child's samples for any new research. Deciding not to participate in this study will not affect your child's medical care in any way. Neither you nor your child's insurance company will be billed for any study procedures. Your child will not receive any money for taking part in this study.

### CONFIDENTIALITY

Your child's identity will be kept private. Genetic information about your child and your family will be kept private. We will not share any information about your child with anyone else in your family. His/her blood sample will be labeled with a code number. The key to the code, which links his/her name to a code number, will be kept in a locked and/or password-protected file. Links between your child's identity and the study code will be available only to people working directly on the research project related to your child. Government or university staff sometimes review studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your child's

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OCT 22 2010

records may be examined. The reviewers will protect your child's privacy. The study records will not be used to put your child at legal risk of harm. If you decide to release study information, it may change your or your child's health or life insurance.

### OPTIONS TO CONSIDER WHEN PARTICIPATING IN THIS STUDY

There are several ways listed below that your child can participate in this study. These choices will be included at the end of the consent form with "yes" or "no" answers for you to fill out.

\* If you agree, we would like to keep your child's samples indefinitely. Samples may be used to help find genetic causes of other diseases studied by our lab. These may or may not be related to the disease for which they were originally collected.

Future research using your child's sample may lead to commercial products. Neither you nor your child will share in any profits that this research may produce.

\* If you agree, we may share your child's blood samples with other researchers. Your child's sample will be marked with a special code and will not include his/her name, address, or any other information that can be linked to him/her.

\* If you agree, we may want to contact your child in the future to ask him/her to take part in other studies.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Investigator (Print)

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Review Committee

**Parent's statement:**

This study has been explained to me. I volunteer to have my child take part in this research. I have had a chance to ask questions. If I have questions later on about the research I can ask the investigator listed above. If I have questions about my child's rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

As described above: (please circle YES or NO)

You may keep my child's DNA samples and medical records, including clinical notes, imaging studies, test reports, and pictures indefinitely. YES NO

You may share my child's DNA sample or cell lines with other researchers indefinitely. YES NO

You may contact my child about future studies. YES NO

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Parent #1 Signature Date

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Parent #1 Name (Please Print)

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Parent #2 Signature Date

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Parent #2 Name (Please Print)

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Name of Child Subject (Please Print)

Copies to: Parent, Investigator's file

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