UNIVERSITY OF WASHINGTON
CONSENT FORM
NEUROGENETICS LABORATORY REPOSITORY

Adults 18 years and older

Parents/Guardians of Children younger than 18 years

Assent Form for Children 13-17 years

Deceased Individuals

RECEIVED
Human Subjects Division
AUG 08 2014
UW

Researchers

Daniel Doherty, MD, PhD	Associate Professor	Dept. of Pediatrics	206-987-2489
Ian A. Glass, MD	Professor	Dept. of Pediatrics	206-987-5142
Heather Mefford, MD, PhD	Associate Professor	Dept. of Pediatrics	206-543-9572
William Dobyns, MD, PhD	Professor	Dept. of Pediatrics	206-884-1025
Jennifer C. Dempsey, MPH	Research Coordinator	Dept. of Pediatrics	206-616-3788

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 you 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 to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' We will give you a copy of this form for your records.

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 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.

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Review Committee

STUDY PROCEDURES

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

If you decide to take part in this study, samples of your DNA and/or permanent cell lines from your blood will be stored. We may ask for other samples that are no longer needed for your 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. This includes your 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 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, taking part in this study might make it harder to get health insurance if the results get into your medical record. We will keep all research results separate from your 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 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 medical care. We will talk to your medical provider before giving out any unexpected results.

ALTERNATIVE TO TAKING PART IN THIS STUDY

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

BENEFITS OF THE STUDY

It is unlikely that you 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 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 samples can be used for research, you can change your mind later. Just let us know that you do not want us to use your samples for any new research. Deciding not to participate in this study will not affect your medical care in any way. Neither you nor your insurance company will be billed for any study procedures. You will not receive any money if you take part in this study.

CONFIDENTIALITY

Your identity will be kept private. Genetic information about you and your family will be kept private. We will not share any information about you with other members of your family. Your blood sample will be labeled with a code number. The key to the code, which links your name to a code number, will be kept in a locked and/or password-protected file. Links between your identity and the study code will be available only to people working directly on the research project related to you. 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 records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk of harm. If you decide to release study information, it may change your health or life insurance.

OPTIONS TO CONSIDER WHEN PARTICIPATING IN THIS STUDY

There are several ways listed below that you can take part 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 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 sample may lead to commercial products. You will not share in any profits that this research may produce.

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

* If you agree, we may want to contact you in the future and ask you to participate in other studies.

Signature of Investigator Date

Name of Investigator (Print)

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Subject's statement:

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions about the research, I can ask the investigator listed above. If I have questions about my 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 DNA samples and medical records, including clinical notes, imaging studies, test reports, and pictures indefinitely.	YES	NO
You may share my DNA sample or cell lines with other researchers indefinitely	YES	NO
You may contact me about future studies.	YES	NO

Printed name of subject   Signature of subject   Date

When subject is a minor:

Printed name of parent   Signature of parent   Date

When subject is not able to provide informed consent:

Printed name of representative   Signature of representative   Date

Relationship of representative to subject

Copies to: Subject, Investigator's file