MOUNT SINAI SCHOOL OF MEDICINE
MOUNT SINAI HOSPITAL
RESEARCH SUBJECT AUTHORIZATION

GCO # 07-0916

Protocol Title: **Search for Genes Influencing Childhood Absence Epilepsy**

Principal Investigator: Martina Durner, MD
Mount Sinai Hospital
One Gustave L. Levy Place
Box 1230, New York, NY 10029
Telephone Number: 212-659 8816

Co Investigator(s):

You and your child have agreed to participate in the study mentioned above and have signed a separate informed consent that explained the procedures of the study and the confidentiality of your and your child's personal health information. The federal **H**ealth **I**nsurance **P**ortability and **A**ccountability **A**ct (HIPAA) requires us to give you more detailed information about how we intend to use and share your and your child's health information in connection with this study. We also need to ask your permission to receive, use and share that information.

You authorize the Mount Sinai Hospital, your and your child's doctors and other health care providers to disclose your and your child's health information for the purposes described below:

What personal health information is collected and used in this study, and might also be disclosed (shared)?

The following personal health information will be collected, used for research and may be disclosed or released in connection with this research study.

- Name, Address, Telephone number, Electronic Mail Address, and unique Idenifying Codes to label DNA
- Medical History (includes current and past medications or therapies, illnesses, conditions or symptoms, family medical history, allergies, etc.)
- Medical Records from your neurologist.
- List all other tests and procedures that will be performed in the study: DNA Sample, Interview and EEG

Why is your and your child's personal health information being used?

Your and your child's personal contact information is important to be able to contact you and your child during the study. Your and your child's health information and results of tests and procedures are being collected as part of this research study and for the advancement of medicine and clinical care. This may include monitoring your and your child's health status, measuring the effect of research procedures, to determine research results, and possibly to develop new tests, procedures, and commercial products. The research team may use and share your and your child's information to ensure that the research meets legal, institutional or accreditation requirements.

Which of our personnel may use or disclose your and your child's personal health information?

The following individuals and organizations may use or disclose your and your child's personal health information for this research project:

- The Principal Investigator and the Investigator's study team (other Mount Sinai Hospital and Mount Sinai School of Medicine staff associated with the study).
- The Mount Sinai School of Medicine Institutional Review Board (the committee charged with overseeing research on human subjects) and the Mount Sinai Hospital's and Mount Sinai School of Medicine's Privacy Officers.

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- Authorized members of the Mount Sinai Hospital and Mount Sinai School of Medicine workforce who may need to access your and your child's information in the performance of their duties (for example: to provide treatment, to ensure integrity of the research, accounting or billing matters, etc.).

Who, outside of the Mount Sinai School of Medicine and the Mount Sinai Hospital, might receive your and your child's personal health information?

As part of the study the Principal Investigator, study team and others listed above may disclose your and your child's personal health information, including the results of the research study tests and procedures to the following people or organizations. It is possible that there may be changes to the list during this research study. You may request an up-to-date list at any time by contacting the Principal Investigator.

- United States Department of Health and Human Services and the Office of Human Research Protection.

How long will the Mount Sinai School of Medicine and the Mount Sinai Hospital be able to use or disclose your and your child's personal health information?

Your authorization for use of your personal health information for this specific study does not expire.

Do you have to sign this Authorization?

NO! If you decide not to sign this authorization you will not be allowed in the research study. If you do not sign, it will not affect your or your child's treatment, payment or enrollment in any health plans or affect your or your child's eligibility for benefits.

Can you change your mind?

You may withdraw your permission for the use and disclosure of any of your and your child's personal information for research, **but you must do so in writing** to the Principal Investigator at the address on the first page. Even if you withdraw your permission, the Principal Investigator for the research study may still use your and your child's personal information that was already collected if that information is necessary to complete the study. Your and your child's health information may still be used or shared after you withdraw your authorization if you or your child should have an adverse event (a bad effect) from being in the study. If you withdraw your permission to use your and/or your child's personal health information for research that means you and/or your child will also be withdrawn from the research study, but standard medical care and any other benefits to which you and/or your child are entitled will not be affected. You can also tell us you and/or your child want to withdraw from the research study at any time without canceling the Authorization to use your data.

You will be given a copy of this Research Subject Authorization Form describing your and your child's confidentiality and privacy rights for this study. If you have not already received it, you will also be given the Mount Sinai Hospital - Mount Sinai School of Medicine Notice of Privacy Practices that contains more information about the privacy of your and your child's health information.

By signing this document:

- You are permitting the Mount Sinai Hospital, your and your child's doctors and other health care providers to disclose your and your child's health information to the researcher for the purposes described above.
- You are permitting the Mount Sinai School of Medicine and the Mount Sinai Hospital to use your and your child's personal health information collected about you and your child for research purposes within our institution.

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- You are also allowing the investigators, the Mount Sinai School of Medicine and the Mount Sinai Hospital to disclose that personal health information collected about you and your child to outside organizations or people for research purposes as described above.
- You recognize that your and your child's information may also be used as necessary for your and your child's research-related treatment, to collect payment for your and your child's research-related treatment (when applicable) and to run the business operations of the hospital.
- You recognize that once information is disclosed to others outside Mount Sinai School of Medicine and the Mount Sinai Hospital the information may be redisclosed and no longer be covered by the federal privacy protection regulations.

Notice Concerning HIV-Related Information

If you are authorizing the release of HIV-related information, you should be aware that the recipient(s) is prohibited from redisclosing any HIV-related information without your authorization unless permitted to do so under federal or state law. You also have a right to request a list of people who may receive or use your and your child's HIV-related information without authorization. If you and your child experience discrimination because of the release or disclosure of HIV-related information, you may contact the New York State Division of Human Rights at (212) 480-2522 or the New York City Commission of Human Rights at (212) 306-5070. These agencies are responsible for protecting your rights.

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SIGNATURE

I have read this form and all of my questions about this form have been answered. By signing below, I acknowledge that I have read and accept all of the above.

____
Signature of Subject or Personal Representative

____
Print Name of Subject or Personal Representative

____
Date

____
Description of Personal Representative's Authority

CONTACT INFORMATION

The contact information of the subject or personal representative who signed this form should be filled in below.

Address:
____
____
____
____

Telephone:
____________________ (daytime)
____________________ (evening)

Email Address (optional):
____

THE SUBJECT OR HIS OR HER PERSONAL REPRESENTATIVE MUST BE PROVIDED WITH A COPY OF THIS FORM AFTER IT HAS BEEN SIGNED.