Title of research study: The genetics of childhood neurological diseases

Principal Investigator: Joseph Gleeson, MD.

What will happen to me in this study? — You are being asked to participate in this study because you or someone in your family has a brain disease.

Only if you want to, three things may happen to you if you are in this study:
1. We may take a small amount of your blood with a needle in your arm.
2. We may ask you for a sample of your spit.
3. We will ask you or your parents to answer some questions about your health.
4. We may take some photographs of you that may include your face.

Can anything bad happen to me? — If we draw your blood, you may feel bad from the needle stick. The stick from the needle might hurt but the pain will go away after a while. You should tell your parents if you feel bad. You may get a bruise (black and blue mark) where the blood was taken.

Can anything good happen to me? — This study will not make you better or get well. But, the doctors might find out something that will help other children later.

Do I have other choices? — You can choose not to be in the study.

Will anyone know I am in the study? — Yes. Dr. Gleeson and his research staff and people at the Rockefeller Hospital will know if you are in the study.

What happens if I get hurt? — If you get hurt because of the blood draw the Dr. Gleeson and/or his staff will make sure you get medical attention. For any other medical problems, you will go to your own doctor.

Who can I talk to about the study? — You can talk to your parents or with Dr. Gleeson if you have any questions about the study.

What if I do not want to do this? — You do not have to do this study if you do not want to and no one will be mad at you. If you do not want to be in this study, you just have to tell us.

06/11/14
Pediatric Assent

If you want to be in this study, just tell us. And, remember, you can say “yes” now and change your mind later. It’s up to you.

**SIGNATURE CLAUSE**

If you have any problems with this study, you may call the Institutional Review Board at (212) 327-8410 or the Office of Clinical Research at (212) 327-8408

Are you willing to participate?

☐ YES  ☐ NO

____________________________________  ________________
Signature of Child  Date

____________________________________  ________________
Person Obtaining Assent  Date