

Subject's Name: \_\_\_\_\_  
Title of Research Protocol: The Genetics of Childhood Neurological Diseases  
Investigator's Name: Dr. Joseph Gleeson  
Protocol Number and expiration date: 140028 At the completion of this study

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**University of California - San Diego  
Child Assent Form**

Dr. Joseph Gleeson and the doctors working with him are doing a research study to find out why some children have **certain mental and physical problems**. This research project studies the genes from kids and their parents, to find out which genes lead to these kinds of problems. We are asking you to be in our study because someone in your family either has mental retardation or convulsions or may be at risk for developing these sorts of problems. There will be approximately 800 new participants joining this study every year. To date there have been over 10,00 individuals participating in this project.

If you say "yes" to being in our study, these are the things that will happen to you:

1. One of the people working with Dr. Gleeson may draw some blood (2-3 teaspoons) from your arm or another part of your body, or collect some saliva from your mouth. The blood draw or poke on your finger may hurt a little bit.
2. If you are having surgery, one of the people working with Dr. Gleeson will save some of the unhealthy part of your body that is being removed.
3. If you have something called an HPDL mutation, we might later ask for a little bit more blood. Some doctors might also want to check how your brain is doing by asking you or your family some questions and doing some activities with you to understand how you're feeling. These doctor visits might take 1- 3 hours.
4. One of the people working with Dr. Gleeson may look at your medical record.
5. Your genetic information and diagnosis might be shared on the computer with other scientists but all of your personal information will be kept secret.
6. There are laws that protect your genetic information so that people you may work for in the future, or companies that support your medical care cannot request your genetic information from this project.

Dr. Gleeson or one of the doctors working with him has told you all about the study and have answered all your questions. Be sure to ask Dr. Gleeson or one of his helpers to tell you more about anything you don't understand.

You do not have to be in this study if you don't want to be. You can stop any time you want and no one will be upset or angry with you.

☐ Yes, you agree to be in this research study  
this

☐ No, you don't want to do

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Child's Signature

Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date