**Study Title: Subject Database and Specimen Repository for Neuromuscular and Neurodegenerative Disorders**

1. **What will happen to me in this study?**

   If you want to, you can be in a study to help scientists learn more about the muscle and nerve problems that run in your family. You do not have to be in this study if you do not want to.

   If you decide to be in the study, your name will be included in our database.

2. **Can anything bad happen to me?**
   There is a very small chance of losing privacy.

3. **Can anything good happen to me?**
   There are no benefits in participating.

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

5. **Will anyone know I am in the study?**
   **Confidentiality:**
   The information that you are participating in this study will be kept secret so no one knows. Some information will be given to the study Sponsor, but your name and personal information will be kept secret.

6. **What happens if I get hurt?**
   **Compensation for Participation/Medical Treatment:**
   Your parents/legal guardians have been given information on what to do if you get hurt during the study.

7. **Who can I talk to about the study?**
   **Contact Information:**
   If you have any questions about the study or any problems to do with the study you and your parents or guardians can contact the Protocol Director, Dr. John Day. You can call him at 650-725-7622.

   If you have questions about the study but want to talk to someone else who is not a part of the study, you can call the Stanford Institutional Review Board (IRB) at (650)-723-5244 or toll free at 1-866-680-2906.

8. **What if I do not want to do this?**
   **Voluntary Participation:**
   You can stop being in the study at any time without getting in trouble and your doctor will continue to treat you if treatment is necessary and available.

**SIGNATURE**

If you agree to be in this study, please sign here:

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_____ _____

Signature of Child Date

_____

Printed name of Child