

APPENDIX D
Consent Form
National ALS Registry

Background – ALS is the most common motor neuron disease which causes the deterioration of the upper and lower motor neurons. Motor neurons send signals to the muscles. There are a lot of questions about the number of people who have ALS and what causes it.

Purpose – The purpose of this research is to get a better picture of who gets ALS or other motor neuron diseases. The information could also be used to design studies about what causes ALS. You are being asked to take part because you have ALS. If you decide to register, you will be asked for information about you and where you live. If you take part in any of the survey modules, you will be asked to answer some questions about who you are, where you lived or worked, family history of ALS, hobbies and other activities in which you take part, and how you are coping with your disease. You will only be asked to answer most questions one time. You will be asked to complete questions on how you are coping with your ALS three times in the first year and twice a year thereafter. The survey modules can be done whenever you want. You can do them all at once or over a period of time.

Risks – The major risk of taking part is someone getting your information. To keep this from happening, we will limit who can see your information. We will also have computer security that keeps your information safe.

Benefits – There are no direct benefits to you. In the future, your information could help others with ALS.

Confidentiality – Your information will be kept private to the extent allowed by law. Only authorized individuals will have access to your information. Your information will be stored in a secure location with limited access. Any information that is published about people in the registry will not identify you.

Collaboration – The CDC's National ALS Registry is collaborating with the NIH through the ACT for ALS initiative, to determine who has been diagnosed with ALS. We seek to share your information (e.g., name, date of birth, survey responses) with the NIH securely in order to achieve this goal. Your participation is voluntary.

Results – The website where you registered will have reports about what we learn from people who take part in the National ALS Registry and surveys.

Voluntary – Taking part is up to you. You do not have to take part and you can stop taking part at any time. You will not lose any benefits to which you are entitled if you do not take part or chose to quit.

If you have any questions about the surveys, you can contact Dr. Paul Mehta toll free at 1-877-442-9719. If you have any questions about your rights as a research participant, you can contact the Human Research Protection Office at 1-800-584-8814.

By clicking on I AGREE, you are agreeing to take part.

I Agree – (Go to Patient Registration)

Reject – (Go to ALS registry home page) Flesch-Kincaid Reading Level 8.5