Reset form

Form Approved
OMB No. 0923-0041
Exp. Date 5/31/2026

National Amyotrophic Lateral Sclerosis (ALS) Registry Research Application Form

Date (mm/dd/yyyy):

Title of Study or Project:

Principal Investigator (or Project Director):

Short Title: Organization:

Co-Principal Investigator (if any): (if there are no Co-PI's enter "None.")

Name(s)	Organization(s)	Business Phone Number	Business Email Address

Funding source and any declared (to the IRB) financial conflicts of interest:

Funding source: List the source(s) of funding for the project and this sample, the amount of funding anticipated from each source, and indicate the type of support provided: i.e., grant, contract, cooperative agreement, interagency agreement, other (specify), and note if the funding is current or is pending.

Source(s) of Funding	Amount	Type of Support	Status

Declared conflict of interest: For each investigator please list any financial conflicts of interest declared to the IRB.

Principal Investigator	Conflict of Interest

Summary of Proposed Study Protocol or Project Activities:

Provide a brief summary of your proposed study or project activities. Provide sufficient detail to describe your study or project. If you are requesting data and/or biospecimens or tissues obtained from the National ALS Registry describe how they will be used. Include in this summary the ALS study population in which you are interested, describe the benefit of this study to the community or individuals involved, demonstrate an understanding of the scientific merit of your proposed study, include a description of the hypothesis to be tested and some background information to support why the study or project is being proposed, and include a brief description of your proposed methods and analytic plan. (The summary should be limited to 7000 characters.)

Background:

Specific Aims:

Methods:

Population:

Measures:

Analysis:

Institutional Review Board (IRB) for the Protection of Human Subjects:

(As defined by the U.S. Department of Health and Human Services in the Code of Federal Regulations, Title 45, Part 46):

Evidence of a current IRB approval is required prior to the ATSDR contacting ALS registrants.

Please provide the following information on the IRB to review this project outside of ATSDR:

Name and address of the IRB:

Name:					
Street Address:					
City:		State:		Zip Code:	

IRB Federal Wide Assurance (FWA) number: _____

Does this study have current approval from this IRB? ☐ Yes ☐ No

If Yes, Date of the IRB approval (mm/dd/yyyy): _____

Please provide a lay summary of not more than 250 words that describes the purpose of your research, what information you hope to obtain, who can participate, number of participants, and what participants must do to take part including time commitment. Remember the average high school graduate reads at the 8th grade level so use simple declarative sentences and avoid scientific jargon.

Researcher Agreement

Name of Institution:

Name of Research/Study Covered by this Agreement:

- The researcher will maintain IRB approval at their institution.
- The researcher will not attempt to re-identify the samples or data.
- The researcher will only use the samples or data for the approved project.
- The researcher understands that only approved project staff will be permitted to use samples or data approved for the project.
- The researcher will submit an annual update.
- The researcher will submit any abstracts or manuscripts before submission and allow ATSDR time to review for accurate description of the data/samples and limitations.
- The researcher will submit a copy of each published abstract or manuscript describing the results of such research with the annual update.
- The researcher will submit a copy of the abstract or executive summary of any thesis or dissertation that includes analysis of Biorepository samples or data with the annual update.
- The researcher understands that any project not updated by the deadline will be considered terminated.
- The researcher will submit a final update when the project is completed.
- The researcher understands that ATSDR will contact the Principal Investigator with instructions for handling residual samples and/or data when the project is completed and these instructions must be followed within three months of receipt.
- The researcher will provide results to ATSDR in the requested format.
- The researcher understands that the National ALS Registry and the National ALS Biorepository should be acknowledged in any publication based on analysis of its samples or data.

Researcher Signature: Date:

Print Name: Degree:

Save Form Print Form Email Form