

**ANNUAL UPDATE FORM FOR PROJECTS RECEIVING SPECIMENS AND/OR DATA  
FROM THE NATIONAL ALS REGISTRY OR BIOREPOSITORY**

Date of update (mm/dd/yyyy): \_\_/\_\_/\_\_\_\_

Project #: \_\_\_\_\_

Title of study: \_\_\_\_\_  
\_\_\_\_\_

Principal Investigator: \_\_\_\_\_

Has PI changed since last update?

No     Yes, effective date (mm/dd/yyyy): \_\_/\_\_/\_\_\_\_

Names of all current co-investigators:

\_\_\_\_\_  
\_\_\_\_\_

*NOTE: If this project required IRB approval, please attach copy of the latest continuation approval.*

Project Status (indicate project status:

- Not yet begun
- In progress
- Completed
- Project suspended or terminated (no longer plan to pursue this research project)

Not yet begun? Explain briefly and indicate anticipated start date.

\_\_\_\_\_  
\_\_\_\_\_

In progress? Summarize briefly (2-3 sentences) what has been done in the past year.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Completed? Briefly summarize the results and conclusions.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Project suspended or terminated? Summarize briefly.

\_\_\_\_\_  
\_\_\_\_\_

CDC estimates the average public reporting burden for this collection of information as 15 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0923-0041).

For studies that have been completed, suspended, or terminated, have you contacted ATSDR for instructions on what to do with the remaining samples and data?

- Yes
- No

Have you had any abstracts or articles published since the last update?

- Yes
- No

If yes, list the citation for abstracts or articles published. Also include the meeting name and location for presentations.

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*For those who received samples from the biorepository.*

To help us provide better services and make sure the samples you need are available at a later date, please answer the following question:

Do you anticipate using ALS specimens in the coming year? • Yes • No

If so, which types of samples will you need? (Select all that apply)

- |        |                            |
|--------|----------------------------|
| Blood  | Brain                      |
| Plasma | Spinal cord                |
| Serum  | Cerebral spinal fluid      |
| Urine  | Muscle                     |
| RNA    | Primary dermal fibroblasts |
| DNA    | Bone                       |
| Hair   | Unsure                     |
| Nails  |                            |

Approximately how many samples will you need?

- |           |           |
|-----------|-----------|
| 0 - 10    | 200 - 300 |
| 11 - 50   | > 300     |
| 50 - 100  | Unsure    |
| 100 - 200 |           |

What types of technology do you use in your research? (Select all that apply)

- |                       |                                      |
|-----------------------|--------------------------------------|
| RNA isolation         | Microarray gene expression profiling |
| DNA isolation         | PCR                                  |
| Protein isolation     | FISH/CGH                             |
| Laser microdissection | Proteomics                           |
| Immunohistochemistry  | Gene mapping/SNP analysis            |
| RT/PCR                | Mutation analysis/sequencing         |
| RNA amplification     |                                      |

Enzymology  
Immunoblot/immunoprecipitation  
Pharmacogenomics

Pharmacokinetics  
Serology/antibody studies  
Biomarker analysis

NOTE: All project updates are due by the anniversary of your approval. Any projects either actively terminated or not updated by the deadline will have the project status changed to “terminated”. If you wish to continue the project, a new proposal would be required. New proposals by other researchers may be submitted on these topics.

A final update for each project should be submitted when the project is complete. The final update should include citations for all published manuscripts and abstracts based on the project.