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.

____________________________________________________________________________________
____________________________________________________________________________________

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

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.