

Part A - Research Notification

Will any of the information (obtained from the National ALS Registry, or from the request for ATSDR to inform ALS registrants about the proposed study) be used as a basis for legal, administrative, or other actions which may directly affect particular individuals or establishments as a result of their specific identification in this project?

Yes No Maybe

Will any of the information (obtained from the National ALS Registry, or from the request for ATSDR to inform ALS registrants about the proposed study) be used as a basis for marketing purposes, including, but not limited to, marketing of pharmaceutical drugs?

Yes No Maybe

The following variables* are available for all registrants and can be used to prescreen registrants for notification about your study. Please indicate which variables you would like us to use and specific criteria.

- Specific Age Range at Diagnosis (e.g. 40-49, 50-59, 60-69):
- Specific year/years of diagnosis (e.g. 2012 - current):
- Specific Sex (e.g. female only, male only, both):
- City and/or State(s) of residence or region of the United States (e.g. Los Angeles, CA, Dallas, TX, State of Arizona, State of Georgia and Florida):

*Additional variables are available on a subset of the population, such as registrants with a history of military service, smoking / alcohol consumption or specific ALSFRS-R score. If you wish to use these as eligibility requirements, please contact the ALS Research Notification System Administrator.

I do not want to prescreen for eligibility (e.g. I want to have research materials sent to all participants taking part in the notification process.).

* Requests to have ATSDR identify additional variables for eligible participant(s) may delay the distribution of research materials. If you have questions or concerns about the application process or status of your application, please contact the ALS Research Notification System Administrator at 877-442-9719 (Monday through Friday, 9am to 5pm ET). You may also send us an email at ALSResearch@cdc.gov.

ATSDR kindly requests that researchers include the following acknowledgement in any publications deriving from the study:

“Recruitment for this study was in part made possible by ATSDR’s National ALS Registry Research Notification Mechanism (<http://www.cdc.gov/alsresearch/ALSRecruitmentAssistance.html>)” and that they forward such publications to ATSDR (ALSResearch@cdc.gov).

