

ALS Research Notification Researcher Quick Start Guide

Thank you for your interest in the National Amyotrophic Lateral Sclerosis (ALS) Registry's ALS Research Notification tool. Using this, researchers can have email notifications about their approved studies, including clinical trials, sent to persons with ALS (PALS) who are enrolled in the Registry. The Agency for Toxic Substances and Disease Registry will send emails about research studies only to PALS who have agreed to receive such emails. This guide provides step-by-step instructions for completing, submitting and checking the status of an application.

How to start the application process

Step One: On the National ALS Registry homepage, go to the “ALS Research Notification” section under Registry Topics. This will take you to the ALS Research Notification page.

Step Two: On the ALS Research Notification page, go to the “Researcher Information” box and click the “Researcher Information” button. This will take you to the Researcher Information page.

Step Three: On the Researcher Information page, go to the “Submit Application” box and click the “Submit Application” button. This will take you to the Research Notification Application page.

Step Four: On the Research Notification Application page, click on the link located at the top of the page to open the “National ALS Research Notification Application” pdf web form. This form will open in a new window. Complete and save the document on your computer and make note of its location. When finished close the “National ALS Registry Notification Application” web form.

Step Five: Complete all of the required fields on the Research Notification Application page and attach a copy of the following materials in the “Research Notification Submission Form” before submitting your application:

- Research Notification Application Form.
- Cover letter with a brief overview of the project, highlighting the importance of the research proposal.
- PI CV or Biosketch.
- Full study protocol, including consent form.
- Recruitment letter and informational materials to be sent to potential study participants.
- Confirmation of IRB approval of full protocol and informational materials.
- Additional supporting documentation (not required).

Please note that all attachments have to be in pdf format and must not exceed the size limitation of 30MB combined.

Click the “Submit” button located at the bottom of the “Research Notification Submission Form”. Once your application is submitted, you will be taken to the Research Notification Application Received page. This page will provide you a tracking number to check the status of your application during the review process.

How to track the status of your application

Step One:

On the Researcher Information page, go to the “Application Status” box and click the “Application Status” button. This will take you to the Research Notification Application Status page.

Step Two:

On the Research Notification Application Status page, go to the “Research Notification Application Status” box and enter your tracking number into the text box.

Step Three:

Click the “Track Application” button located next to the “Tracking Number” field. The system will display the status of your application. ATSDR estimates the approval process could take up to 60 business days from the receipt of a complete application.

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-6pm ET). You may also send us an email at ALSResearch@cdc.gov.