**QUICK START GUIDE TO THE** 

# **ALS Risk Factor Surveys**



ALS researchers need as much information as they can gather about people diagnosed with ALS. There are many unanswered questions, and your story could help researchers answer these questions. Your participation in the National ALS Registry is important to piecing together the puzzle of ALS.



### What Do I Need to Begin?

A device that is connected to the internet and an active account with the National ALS Registry.

If you cannot remember your login information, you can contact the National ALS Registry (see contact information at the bottom of the page).

## **How Can I Prepare to Complete the Surveys?**

The surveys collect information about different factors that could affect your risk for ALS. It can be helpful to collect the following information or find a family member who can help you answer these questions.

- Basic demographic information (your name, date of birth, date of diagnosis, etc.)
- **Family history** (family members diagnosed with ALS or other neurodegenerative diseases)
- Military history
- Residential history
- Work history
- Physical activity
- Other risk factor information (environmental exposures such as pesticides and metals, smoking and alcohol use, head and neck injury, etc.)
- Thoughts on your ALS diagnosis

You do not have to complete all the surveys at once. The Registry will save your progress and you can come back to work on it when it is convenient for you or when you have assistance.



### Can I Change My Answers to the Surveys?

At the end of each survey, you'll have the chance to review and edit the answers you saved prior to submission. It is important that the information you enter when filling out these surveys is accurate because you cannot change your answers after you have submitted each survey.



#### What's Next?

#### Join the National ALS Biorepository

and give samples of your biological material. This is a free service, and your participation helps researchers study genetic variations and possible biomarkers for future therapeutic developments.

Sign up for Clinical Trial Notifications.



