Enrolling in the National ALS Registry

Information to Help You Join the National ALS Registry.

Who Can Sign Up?

Any adult with ALS in the United States can join the National ALS Registry. If you have a related disease, such as PLS, PMA, or PBP, you will not be able to register at this time.

Will My Information Be Private?

Yes, all information collected by the National ALS Registry is confidential and not shared with anyone.

What Do I Need to Enroll?

- A computer or device (e.g., tablet or phone) with internet access
 - What if I don't have access to a computer?
 - You can ask a family member, caregiver, or friend to borrow their computer.
 - You can contact your ALS advocacy organization, and someone can help you through the process.
- An email address
- Social security number (the last 5 digits only)
 - Please note, your information is never shared with anyone.
- Although not necessary, it can be helpful to enroll with a caregiver or family member to help.

Where Do I Enroll?

cdc.gov/als



How Much Time Do I Need to Enroll?

Enrolling in the Registry is a quick process, and it usually takes about 5-10 minutes. You may have heard about the Registry's risk factor surveys. You do not need to complete all of these at the time of enrollment and can complete them at your leisure. Courtesy reminders will also be sent to your email address. Your progress will be saved, and you can come back to explore other parts of the Registry.

Where Can I Go for Help?



cdc.gov/als



Email: als@cdc.gov



877-442-9719Monday–Friday
8 AM–5 PM EST

What's Next?

Complete the Risk Factor Surveys.

For more information, see the Quick Start Guide to the ALS Risk Factor Surveys or visit <u>cdc.gov/als</u>

