

How will my information be protected?

Persons with ALS are asked to give personal identifiable information when joining the National ALS Registry. This information is a necessary part of enrolling in the registry.

The registry collects personal identifiable information such as your name, last 5 digits of your social security number (SSN), and your date of birth. Some fields needed to register will be hidden to ensure the security of your data. All of your data are encrypted in the registry database. Every night we move the personal identifiable information of the people who registered during that day to a secure database. This database is not linked to the Internet.

We use the partial SSNs to compare cases in the Web portal with those in the large national databases. The partial SSNs help us make sure each participant is only counted once. Only scientists approved to work on the National ALS Registry can see participant information. The data collected through the registry are used only for official business.

Doctors and scientists requesting registry data cannot access information that would identify individual participants. Any information published about people in the registry will be group information. It will not identify any individual participants.