

Hello all,

The ALS Association is partnering with The California NeuroAlliance, an advocacy partnership representing millions of Californians affected by neurological conditions, their advocates and their doctors. The coalition's purpose is to improve the quality of life of those affected by neurological conditions by promoting access to quality health care through education, public awareness and advocacy.

With organizational support from the American Academy of Neurology and financial support from The Medtronic Foundation, The California NeuroAlliance has developed a survey tool that will allow the collection of information from Californians affected by neurological conditions that might not otherwise have a voice. The information provided by patients, caregivers and family members will help legislators, other public officials and health plan providers better understand and hopefully better meet the needs of those they serve. The information gathered via the survey will be put into action through data-driven advocacy by The California NeuroAlliance.

### **Frequently Asked Questions about The California NeuroAlliance Consumer Survey**

#### **What is it?**

The California NeuroAlliance and the American Academy of Neurology have created an easy to use, online survey tool to gather important information from Californians affected by or living with a neurological condition.

#### **How will information from this survey be used?**

Each year, the California NeuroAlliance and its members meet in Sacramento to advocate on important policy issues at the capitol. We will use the information from this survey to help educate elected representatives, healthcare executives, and the public about the critical healthcare needs of people living with neurological conditions.

We will also use the information to promote better healthcare decisions by private healthcare organizations.

The information from this project will help ensure that *their* decisions reflect *consumer* needs.

#### **Will consumers' individual information become public?**

No. Information from this survey will only be released in an aggregate or combined form that includes the information from a large number of people who complete the survey. No information from this survey that could identify individuals will ever become public.

#### **The survey asks for the last 4 digits of someone's Social Security number. Why? Is this a concern for identity theft?**

The sole purpose of asking for the last 4 digits of Social Security numbers is to ensure that someone only takes the survey once and that the data we collect are valid. No, this will not lead to identity theft. All the information is stored in an encrypted database, and in no case will ever be part of any public reports.

#### **Who are the target audiences for the survey information?**

The survey is meant for anyone in California with a neurological condition.

### **Can individuals with conditions not represented on the website take the survey?**

Yes. We have included a generic survey that is almost identical to the condition-specific versions on this website. Responses will be included in the collected data used by the California NeuroAlliance in its advocacy efforts.

### **Can individuals not living in California take the survey?**

Yes. Although at this time our focus is on Californians with neurological conditions, the American Academy of Neurology and member organizations of the California NeuroAlliance hope to expand this effort nationally.

By including zip codes, respondents from other states can be sorted and reports can be generated for other areas of the country. And, their participation will help us demonstrate the importance of a national version of this important survey and advocacy tool.

### **How does someone complete the survey?**

Individuals can complete the survey in three ways:

1. Online: Go to [www.calneurosurvey.com](http://www.calneurosurvey.com) and then click on the appropriate neurological condition or the "other neurological condition" link. You will then be given a chance to "create login" and begin the process. When you click on this link, you will be asked to create a unique username and password. If necessary, at any point, respondents can save their replies, exit the survey and return later to complete it.
2. Paper survey printed online: Go to [www.calneurosurvey.com](http://www.calneurosurvey.com) and then click on the appropriate neurological condition or the "other neurological condition" link. Instead of logging in, click on the "print survey" option and then print from the Internet browser.

Complete the paper survey and submit to the designated organizational contact (indicated at the top of the survey) by fax or mail.

3. Paper survey from your organization: Each organization participating in this project may distribute paper versions of the survey through support groups or direct mail. If so, please make sure that completed surveys are faxed or mailed back to your organization for data entry.