

Capital Office 601 Pennsylvania Avenue, N.W.
Suite 900, South Bldg.
Washington, DC 20004

Telephone 202/638-6997
Fax 202/638-6316

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Via Electronic Mail: omb@cdc.gov

Maryam I. Daneshvar
Acting Reports Clearance Officer
Centers for Disease Control and Prevention
1600 Clifton Road
MS-D74
Atlanta, GA 30333

RE: Proposed Data Collections Submitted for Public Comment and Recommendations [60Day-0923-09BR]

Dear Ms. Daneshvar:

The ALS Association is the only non-profit organization fighting Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's Disease on every front. By supporting global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association enhances quality of life while aggressively searching for new treatments and a cure.

The Association also led the advocacy effort behind the enactment of the ALS Registry Act (P.L. 110-373), which amended the Public Health Service Act to provide for the establishment of an ALS Registry at the Centers for Disease Control and Prevention (CDC). Accordingly, we are pleased to submit the following comments regarding the *Proposed Data Collections Submitted for Public Comment and Recommendations [60Day-0923-09BR]* Federal Register Notice for your consideration.

The Association agrees that the proposed collection of information through a combination of existing sources of information and a public web site is essential and appropriate to fulfill the intent of the ALS Registry Act. In particular, we believe that self-identification of ALS patients through the web site mechanism will be important to capture individuals who are not otherwise included in the registry data base through other data acquisition strategies. A robust web portal can be a valuable part of obtaining accurate estimates of ALS, as well as other benefits of the registry.

In addition, it will be critical to design both the web portal and the entire ALS patient identification system in a way that optimizes accurate ALS patient identification while preventing duplication of information or other errors. The ALS Association further agrees with the agency's proposal to use the web-based registration to enable a survey tool. This will be a dynamic tool for assessing the community around key issues.

Through these strategies, The Association believes that the ALS Registry should:

- promote opportunities to participate in clinical trials;



Member National Health Council

- provide access to research information; and
- facilitate a working partnership between patients and researchers.

Moreover, The Association envisions this system, especially the interactive web site, as a mechanism to help inform providers and researchers about ALS, as well as to promote an enhanced relationship between patients/caregivers and clinicians. The web site feature should:

- address patient questions;
- guide patients to clinical care;
- inform primary and specialty care providers; and
- deliver scientifically sound information and resources.

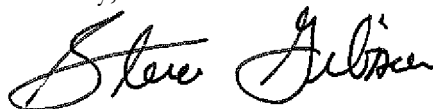
The Association is in a position to assist the CDC and ATSDR in assuring the quality, utility, and clarity of the patient information collected for the National ALS Registry. We believe that the Registry web site should affirmatively link patients, their caregivers, and other stakeholders to The Association's resources also available on the web, in print format, or through our points of service across the country. The Association also will undertake efforts to promote and otherwise encourage the ALS community to participate in the National ALS Registry through the proposed CDC web portal. The Association anticipates partnering with the CDC to promote the web portal, including through our more than 40 Chapters and affiliates located across the country, ALS Association Certified Centers of Excellence and ALS clinics, via communications directly to people with ALS and their families, and via The Association's website, which receives an average of more than 48,000 visitors per month.

Beyond the elements discussed above, The Association also encourages the agency to consider the following elements for the Registry web site:

- relevant research study and clinical trial information (*e.g.*, a link to clinicaltrials.gov);
- capability to authorize an email of current studies and/or clinical trials to registry participants in which they might be eligible to participate;
- capability for participants to elect to authorize study teams to contact the patient or caregiver directly when matched with a study; and
- published research findings on environmental, genetic, and other factors in ALS.

Thank you for the opportunity to provide comment on the proposed data collection strategies, including the website. The entire ALS Association looks forward to the timely completion of the National ALS Registry.

Sincerely,



Steve Gibson
Vice President, Government Relations and Public Affairs