



September 8, 2009

Steve Gibson  
Vice President, Government Relations and Public Affairs  
ALS Association  
601 Pennsylvania Avenue, N.W.  
Suite 900, South Bldg.  
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Dear Mr. Gibson,

Thank you for your letter responding to Proposed Data Collections Submitted for Public Comment and Recommendations [60Day-0923-09BR, July 27, 2009]. We appreciate the ALS Association's (ALSA's) comments and interest in the Agency for Toxic Substances and Disease Registry's (ATSDR's) work on evaluating the feasibility of establishing a National Amyotrophic Lateral Sclerosis (ALS) Registry.

We agree with ALSA that self-enrollment of ALS patients through ATSDR's public web portal, in addition to the use of existing administrative data sources, is an important mechanism for increasing both the accuracy and completeness of the National ALS Registry. As requested in your letter, ATSDR's ALS web portal will also provide access to research information and will promote opportunities to participate in ALS clinical trials, as there will be a link to [www.clinicaltrials.gov](http://www.clinicaltrials.gov). ATSDR's ALS web portal will also inform visitors about ALS in general through frequently asked questions (FAQs) and deliver scientifically sound information and resources through links to sites such as the National Institutes of Health's (NIH) ALS webpage.

Because ATSDR must maintain impartiality, we cannot "guide patients to clinical and specialty care providers" as suggested by ALSA; however, we will have links to the websites of ALSA and other ALS support organizations, which contain such information. Regarding "the capability to authorize an email of current studies and/or clinical trials to registry participants" and the "capability for patients to authorize study teams to contact registry patients," ATSDR does not have the authority to contact registry participants directly because of OMB regulations; however, we feel confident that registry participants will have access to current studies and/or clinical trials through the links mentioned above.

We genuinely appreciate ALSA's continued interest and offers to assist ATSDR in

promoting and encouraging participation of the ALS community in the National ALS Registry. Furthermore, ATSDR looks forward to a continuing relationship with ALSA and other key organizations as we work to obtain critically needed information on the national distribution of ALS for patients, researchers, and advocates for those with ALS.

Sincerely yours,



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