



September 8, 2009

Valerie Cwik, M.D.  
Senior Vice President – Research & Medical Director  
Muscular Dystrophy Association  
3300 East Sunrise Drive  
Tucson, AZ 85718-3299

Dear Dr. Cwik,

Thank you for your letter RE: Proposed Data Collections Submitted for Public Comment and Recommendations [60Day-0923-09BR, July 24, 2009]. We appreciate the Muscular Dystrophy Association's (MDA'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. The following is our response to your technical recommendations for design and implementation of a National ALS Registry.

Although we agree that data provided by physicians would be desirable, this is not a feasible approach because there is no legislation requiring physician reporting and experience has shown that, even with legislation physicians do not make good "reporters". As stated during the Annual ALS/MS Surveillance meeting in Atlanta June 24-25, 2009, ATSDR will be developing a national ALS Registry using two major sources of data: (1) existing national administrative databases (e.g., Veterans Health Administration, Veterans Benefits Administration, Medicare and Medicaid) and (2) self-identification of ALS patients. The latter will be especially important in capturing individuals who would not be included in the administrative databases. ATSDR is currently completing work on developing an interactive ALS Registry portal. We believe that by using the validation questions developed by the Veterans Administration for their ALS Registry we will successfully identify volunteers who truly have ALS.

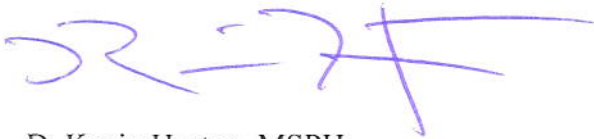
We agree that the National ALS Registry should facilitate a good working partnership among ALS patients, caregivers, clinicians and researchers. ATSDR is currently identifying key individuals to establish an Advisory Committee that will oversee the National ALS Registry. Also, we are working on enhancing our collaborations with existing ALS registries; state, local and federal partners; national ALS patient advocacy groups and clinicians in promoting and encouraging the ALS community to participate in the National ALS Registry. ATSDR does not intend to replace privately operated

registries but will work with them to assure data compatibility. It should be noted that ATSDR already has a link to the MDA website among a few key sources shown on the ATSDR ALS portal's front page.

As the ALS Registry matures, we intend to add surveys that will collect additional information about the demographics of those with ALS and possible risk factors for ALS. Participants in the ALS Registry will be able to participate in these additional data collection activities. They will also be able to generate reports summarizing the information and view or download reports created by ATSDR.

Thank you for your continued interest and support. ATSDR looks forward to a productive relationship with MDA 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,



D. Kevin Horton, MSPH  
Chief, Surveillance and Registries Branch  
Division of Health Studies  
Agency for Toxic Substances and Disease Registry  
4770 Buford Highway, Mailstop F-57  
Atlanta, GA 30341-3717  
Tel (770) 488-1555  
Fax (770) 488-7187  
[dhorton@cdc.gov](mailto:dhorton@cdc.gov)  
<http://www.atsdr.cdc.gov>

cc: Oleg Muravov, ATSDR, Medical Epidemiologist  
Betsey Dunaway, CDC, Privacy Officer  
Maryam Daneshvar, CDC, Clearance Officer  
Annie Kennedy, MDA, VP Advocacy