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Dear Colleague,

I wanted to make you aware of an important project in the effort to find a cure for ALS. The Agency for Toxic Substances and Disease Registry (ATSDR) is the federal agency with the Department of Health and Human Services responsible for creating and maintaining the National ALS Registry mandated by Congress. The National ALS Registry is currently comprised of cases gathered from several administrative datasets including, the Centers for Medicaid and Medicare Services (CMS), the Veterans Health Administration (VHA), and the Veterans Benefits Administration (VBA), as well as self-registered individuals. To evaluate the completeness of the National ALS Registry, ATSDR is supporting the creation of state based surveillance projects in three states, Florida, New Jersey and Texas and metropolitan area based surveillance projects in three cities, Atlanta, Detroit and Philadelphia. In addition, these projects will assist the states and metropolitan areas in obtaining quality data about those with ALS in their areas. These projects are being conducted by McKing Consulting Corporation and their state and local health department partners. Patient consent and HIPPA authorization are not needed to report cases because this is a public health investigation. In addition, the project has been approved by the CDC/ATSDR IRB.

I believe that this project is an important component in the fight to find a treatment and cure for ALS. It will collect vital information about cases of ALS that not only can help improve the quality of care for people with ALS, but also identify the causes of ALS and ways to treat and, ultimately, cure the disease. I have been working with ATSDR on the creation of the National ALS Registry and am currently consulting on the state- and metropolitan area-based surveillance projects. As a neurologist who treats individuals with ALS, I want to encourage your participation in this project. You will be contacted by the surveillance coordinator in your area in the near future to answer any questions you have about the project. If you would like to talk to someone before then, you can contact the Project Director, Dr. Wendy E. Kaye at ALSsurveillance@mckign.com.

Sincerely,



Eric Sorenson, MD