

Attachment 9: Protocol Appendix C3 - ATSDR Endorsement Letter



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Agency for Toxic Substances
and Disease Registry
Atlanta, GA 30333

October 27, 2014

Wendy E. Kaye, PhD
Project Director
McKing Consulting Corporation
2900 Chamblee Tucker Road
Building 10, Suite 100
Atlanta, GA 30341

Dear Dr. Kaye:

The Agency for Toxic Substances and Disease Registry's (ATSDR) Division of Toxicology and Human Health Sciences is happy to endorse the Promotion of the National Amyotrophic Lateral Sclerosis (ALS) Registry to Non-referral Centers and we are very pleased to be able to fund this project. ATSDR is responsible for developing and maintaining the congressionally-mandated National ALS Registry. As noted on our website (www.cdc.gov/als), "The National ALS Registry is a program to collect, manage, and analyze data about persons with ALS (PALS). It includes data from existing national databases and information provided by persons with ALS who choose to participate. Researchers can use Registry data to look for disease pattern changes over time and try to identify whether there are common risk factors among PALS. Additionally, the Registry provides updated links for participant resources like ALS clinical trials."

We understand that your project will pilot test educational and promotional outreach activities among select non-referral/non-specialty center neurology practices to inform the neurologists and their staff about the Registry, to encourage them to inform their ALS patients about the Registry, and to increase persons with ALS self-enrollment in the Registry's web portal. These activities will support ATSDR in fulfilling its congressional mandate.

ATSDR is pleased to partner with McKing Consulting Corporation to lead the way on this groundbreaking effort against ALS, and we hope that you will be successful in your efforts to work with the non-referral center neurological community throughout the United States.

Thank you for your assistance with this important initiative.

Sincerely,

D. Kevin Horton, DrPH, MSPH
Chief, Environmental Health Surveillance Branch
Division of Toxicology and Human Health Sciences