

[ON TEXAS LETTERHEAD]

DATE

[Name of contact]

[Title of contact]

[Address]

[City, state, zip]

Dear [CONTACT NAME],

The Texas Department of State Health Services (DSHS) is partnering with the Agency for Toxic Substances and Disease Registry (ATSDR), a federal public health agency within the U.S. Department of Health and Human Services, on a state-based Amyotrophic Lateral Sclerosis (ALS) Surveillance Project as part of the National ALS Registry. The purpose of the state-based project is to accurately determine the incidence and prevalence of ALS in Texas and the demographic characteristics of those suffering from the disease. Compensation will be provided to medical providers who fill out a short form for each patient diagnosed and/or treated with ALS between January 2009 and December 2011. Medical providers also may be asked on occasion to complete a longer form on select patients as part of the quality assurance process.

The Texas ALS Surveillance Project (IRB # 10-036) has received approval through DSHS IRB#1 and a CDC/ATSDR IRB. The authority to request information for the project is provided in the Code of Federal Regulations, 45 CFR 164.512(b). This section permits covered entities to release private health information to a public health authority that is authorized by law to collect and receive information for preventing and controlling disease, injury, or disability. This information includes reporting of disease, injury, vital statistics like births, deaths, marriages, divorces, etc., public health investigations, and public health interventions. Under this exception you are authorized to release information to DSHS, or other public health authorities, and you are exempt from HIPAA requirements. Disclosure can be initiated either by the public health authority or you, if it is for one of the above reasons.

In the coming months, the ALS Surveillance Project Coordinator will contact your medical practice to schedule a visit, during which all aspects of the Project will be discussed. If you do not see ALS patients, please contact Jessica Keralis, ALS Surveillance Project Coordinator, at (512) 458-7111 ext. 6542 and you will not be contacted.

If you have questions or would like to schedule an appointment, please contact Jessica Keralis, ALS Surveillance Project Coordinator, at (512) 458-7111 ext. 6542.

Thank you in advance for your support of the Texas ALS Surveillance Project.

Sincerely,

Principle Investigator to sign letter

[ON NEW JERSEY LETTERHEAD]

DATE

[Name of contact]

[Title of contact]

[Address]

[City, state, zip]

Dear [CONTACT NAME],

The New Jersey Department of Health and Senior Services (NJDHSS) is partnering with the Agency for Toxic Substances and Disease Registry (ATSDR), a federal public health agency within the U.S. Department of Health and Human Services, on a state-based Amyotrophic Lateral Sclerosis (ALS) Surveillance Project as part of the National ALS Registry (www.cdc.gov/als). The purpose of the state-based project is to accurately determine the incidence and prevalence of ALS in New Jersey and the demographic characteristics of those suffering from the disease. Compensation will be provided to medical providers who fill out a short form for each patient diagnosed and/or treated with ALS between January 2009 and December 2011. Medical providers also may be asked on occasion to complete a longer form on select patients as part of the quality assurance process.

The New Jersey ALS Surveillance Project is public health surveillance, and as such, protected health information may be disclosed by medical providers to the NJDHSS without patient authorization. The authority to request information for the project is provided in the Code of Federal Regulations, 45 CFR 164.512(b). This section permits covered entities to release private health information to a public health authority that is authorized by law to collect and receive information for preventing and controlling disease, injury, or disability. This information includes reporting of disease, injury, vital statistics like births, deaths, marriages, divorces, etc., public health investigations, and public health interventions. Under this exception you are authorized to release information to the NJDHSS, or other public health authorities, and you are exempt from HIPAA requirements. Disclosure can be initiated either by the public health authority or you, if it is for one of the above reasons. Security measures are in place to protect patient privacy and data confidentiality. Patients will not be contacted for the Project.

In the coming months, the ALS Surveillance Project Coordinator will contact your medical practice to schedule a visit, during which all aspects of the Project will be discussed. If you do not see ALS patients, please contact Heather Jordan, ALS Surveillance Project Coordinator, at (609) 984-0057 and you will not be contacted.

If you have questions or would like to schedule an appointment, please contact Heather Jordan, ALS Surveillance Project Coordinator, at (609) 984-0057.

Thank you in advance for your support of the New Jersey ALS Surveillance Project.

Sincerely,

Christina G. Tan, MD, MPH
State Epidemiologist/Assistant Commissioner
Epidemiology, Environmental and Occupational Health

[ON FLORIDA LETTERHEAD]

Date

Dear Dr. X:

The Florida Department of Health is partnering with the federal Agency for Toxic Substance and Disease Registry (ATSDR) on a state-based Amyotrophic Lateral Sclerosis (ALS) Surveillance Project (Project). The purpose of the Project is to accurately determine the incidence and prevalence of ALS in Florida, and to determine demographic characteristics of those suffering from the disease.

Medical providers who diagnose and/or treat patients with ALS between January 2009 and December 2011 will be asked to complete a short form for each case. Medical providers may also be asked on occasion to complete a longer form on select patients as part of the quality assurance process. Compensation for the provider's time and effort will be available.

The Project is public health surveillance, and as such, protected health information may be disclosed by medical providers to the Florida Department of Health without patient authorization. Security measures are in place to protect patient privacy and data confidentiality. Patients will not be contacted for the Project.

In the coming months, your medical practice will be contacted by the Florida Department of Health's ALS Surveillance Project Coordinator to schedule a visit, during which all aspects of the Project will be discussed. If you have questions or would like to schedule an appointment, please contact Cecilia Galvan, ALS Surveillance Project Coordinator, at 850-245-4444, ext. 2171.

Thank you in advance for your support of the Florida ALS Surveillance Project.

Sincerely

Dr. Youjie Huang
Chronic Disease Epidemiologist