## NJ Tracking Provides Public Access to Statewide New Jersey Amyotrophic Lateral Sclerosis (ALS) Surveillance Data

What was the problem/situation?

Amyotrophic lateral sclerosis (ALS) is a rare, incurable, progressive neurological disease which causes muscle weakness, impacts physical function, and eventually leads to death. ALS is not a notifiable disease in the U.S., and population-based ALS incidence, prevalence, and survival time have not been well established in U.S. populations. To help learn more about the disease, the federal Agency for Toxic Substances and Disease Registry (ATSDR) has created the National ALS Registry (Registry). The Registry identifies ALS cases using national administrative databases maintained by Medicaid, Medicare, the Veterans Health Administration, and the Veterans Benefits Administration, and by patient self-enrollment through a secure web portal. This non-traditional case ascertainment had not been validated. New Jersey was one of three states and eight metropolitan areas funded by ATSDR to conduct surveillance projects to ascertain the incidence and demographic characteristics of ALS in defined geographic areas, and to provide data to ATSDR to assist in evaluating the completeness of the Registry.
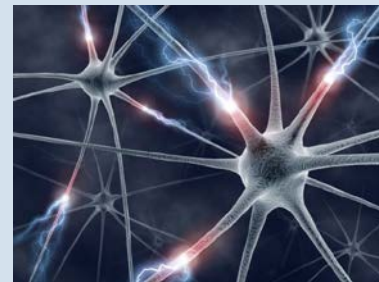
How was Tracking involved?

New Jersey Tracking Principal Investigator, Dr. Jerald Fagliano, served as the Principal Investigator for the New Jersey Department of Health (NJDOH) ALS surveillance project. NJDOH worked with ATSDR scientists to design, implement, and evaluate the first ever New Jersey assessment of ALS incidence, point prevalence, and survival time. Tracking staff collaborated to evaluate the geographical variation of incident ALS cases. Following the completion of the project, Tracking staff collaborated with ALS Project staff to create a new ALS indicator, available on the NJ Tracking data

portal, and a poster summarizing the ALS project for chronic disease directors. The poster will be presented at the upcoming EPHT Virtual Conference. This is the first time NJ ALS incidence and prevalence data have been made available to the general public and the chronic disease communities.

What action was taken to resolve the problem?

NJDOH documented 764 cases of ALS among NJ residents during the three-year period 2009-2011, using extensive outreach to neurologists throughout NJ and surrounding states. The average annual age-adjusted incidence rate was 1.67 cases per 100,000 persons. The point prevalence was 4.4 cases per 100,000 persons as of December 31, 2011. ALS was more common in men compared to women, and increased with age. ALS rates were higher in whites and non-Hispanics compared to other race or ethnicity groups.

The project's findings provide the first ever assessment of state-wide ALS incidence and prevalence in NJ. Data are now available by age, ethnicity and gender, and provide useful information for clinicians, advocacy groups, and ALS patients and their families. This collaboration illustrates how Tracking partnerships can enhance chronic disease surveillance and help make chronic disease data available to the general public, health planners, and advocacy organizations.

Publications from the NJDOH's ALS Surveillance Project:

- Jordan, H; Fagliano, JA; Lefkowitz, D; Rechtman, L; and Kaye, WE. Population-based surveillance of Amyotrophic Lateral Sclerosis in New Jersey, 2009-2011. Neuroepidemiology 2014;43:49-56.

- Jordan, H; Fagliano, J; Rechtman, L; Lefkowitz, D; Kaye, W. Effects of demographic factors on survival time after a diagnosis of Amyotrophic Lateral Sclerosis. Neuroepidemiology 2015;44:114-120.

- Henry, K; Fagliano, J; Jordan, H; Rechtman, L; Kaye,W. Geographic variation of Amyotrophic Lateral Sclerosis incidence in New Jersey, 2009-2011. American Journal of Epidemiology; in press.

Additional information on ALS surveillance can be found on the NJDOH website at http://www.nj.gov/health/als/index.shtml.

NJSHAD serves as the main data portal for NJDOH, providing public access to data and information from the entire New Jersey Department of Health, and hosts datasets for the New Jersey Environmental Public Health Tracking (NJEPHT) Program. NJSHAD provides static public health indicators which combine data and information, and dynamic custom public health query tools. The functionality, content, and utility of NJSHAD and the NJEPHT portal are constantly being enhanced.

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