



More Than 15,000 Living with ALS in the US

A new report from the National ALS Registry indicates that between more than 15,000 people in the United States are living with ALS. The report is the most authoritative estimate about the prevalence of ALS in the US, and is likely to remain so as the Registry becomes better known and more people with ALS sign up with it.

The National ALS Registry was established in 2009 to collect better data on the incidence (number of new cases per year) and prevalence (total number of cases) of ALS. In order to determine the number of ALS cases, the Registry combines data from national health databases, including Medicare and Veterans Health databases, with data entered into a web portal by PALS. Algorithms comb the data to identify ALS cases based on medical codes, and to remove duplicates.

Several years ago, the Registry published its first calculation of ALS prevalence, using data from 2010 to 2011. That estimate was 3.9 cases per 100,000 total population (the standard unit for prevalence), or 12,187 cases of definite ALS in the US. Since then, the algorithm has been revised, allowing the authors of the new study to issue a more accurate figure for that same period of 4.3 per 100,000, or 13,282 cases.

The authors also used updated data from both the databases and the web portal to calculate incidence for 2012 as 4.7 per 100,000, or 14,713 cases, and 2013 as 5.0 per 100,000, or 15,908 cases.

The growth in prevalence is likely due to better ascertainment of existing cases, rather than a growth in the number of people with ALS, according to the authors. "Increased awareness of the National ALS Registry through improved public education and outreach by ATSDR and partner organizations also could have resulted in more persons registering in the web portal, thereby resulting in an increased prevalence estimate," they wrote. ATSDR is the Agency for Toxic Substances and Disease Registry, which administers the Registry.

Further refinements of the algorithm are in the works, which should lead to even better (and likely slightly higher) estimates of ALS prevalence. "The National ALS Registry has 'matured' and is probably capturing a larger proportion of the ALS population through its combined methods for case ascertainment," according to Michael Benatar, MD, PhD, Director of the CReATe Consortium. Nonetheless, he said, there is more work to be done. Using a statistical approach called "capture-recapture," investigators at Stanford are attempting to estimate the number of



missing cases – i.e., people not captured through the National ALS Registry’s current ascertainment methods.

The authors could not estimate incidence with the same data, they pointed out, since the time from onset to diagnosis is not well-characterized in the databases; thus it is not possible to say for each case exactly when the disease began.

These data are valuable for health researchers in order to understand the true burden of ALS in the US, and for policy makers and insurers to better understand the scope of the disease and its likely health and financial impact. They may also be useful to people and families living with ALS, who may get a better sense of the large number of others living with the disease across the country.

As many PALS know, the Registry is also connecting PALS with new clinical trials, and is being used to collect specimens from PALS through a new biorepository. Additional information about the National ALS Registry is available at <http://www.cdc.gov/als> or by calling toll-free at 1-877-442-9719.

The CReATe consortium is working closely with the Registry. CReATe investigators Dr. Benatar and Marc Weisskopf, PhD, have also recently received a grant from ATSDR to study the potential impact of the interaction between genetics and environmental exposures on the rate of disease progression in ALS. In addition, CReATe has used the Research Notification Tool to advertise CReATe Connect, a way for patients with ALS, related disorders, and their family members to learn about CReATe research studies they may be able to join. You can find more information on CReATe Connect here:

<https://www.rarediseasesnetwork.org/cms/create/patients/CReATe-Connect>