

FOCUS ON PRACTICE

AAN Outlines Principles and Vision for Future Role in Registries

First Focus: The National ALS Registry

The AAN should evaluate and, where deemed appropriate, promote existing registries with the intent to increase their enrollment, according to an approach proposed by the AAN's Registry Task Force (RTF).

The RTF was formed in September 2011 by President Bruce Sigsbee, MD, FAAN, and charged with making recommendations on whether the AAN should develop its own registry. The RTF, whose members represent various AAN committees, has made its report to the president. At present, the RTF will continue exploring partnerships with other organizations on their existing registries to identify integrating neurology specific measures in their quality improvement registries. The RTF will also handle requests from outside registries to assess degree of participation.

Specifically, the RTF recommended collaborating with the National Amyotrophic Lateral Sclerosis (ALS) Registry—a type of surveillance registry which collects information from people living with ALS to discover the underlying causes of the disease.

The National ALS Registry, launched in October 2010, is a groundbreaking effort in the fight against ALS. Through this registry, the federal Agency for Toxic Substances and Disease Registry (ATSDR) gathers information from patients across the nation to learn more about any shared traits or experiences that could lead to clues about the causes of ALS.

"The ATSDR CDC National ALS Registry is an emerging instrument to provide leads nationally to the potential environmental causes of ALS," said Benjamin R. Brooks, MD, a member of the RTF.

Patient data is collected from multiple national databases as well as directly from people living with ALS via web portal registration. The more patients who enroll in the registry, the more accurate the registry data will be.

For that reason, it's of paramount importance to encourage your patients with ALS to join the registry and complete Risk Factors Surveys, which are an integral part of the registry. The first six surveys can be completed only one time. The seventh, "Quality of Life," survey should be completed every six months to help measure patients' disease progression. Patients will be notified by email when the Quality of Life survey becomes available.

The registry also links ALS patients with scientists who are recruiting for research. Patients enrolled in the National ALS Registry will receive automatic notification about new clinical trials and other studies for which they might be eligible.

The role of physicians in encouraging registry participation cannot be overlooked. According to the National ALS Registry, over 16 percent of patients with ALS heard about the registry from their doctor. More patients would enroll

if neurologists discussed the participation in the registry on a regular basis.

Physicians can earn a free 1.5 CME credit via the online ALS Continuing Education Module developed

as part of the National ALS Registry for primary care physicians and neurologists without ALS expertise. You can learn more about the ALS Continuing Education Module at www.atsdr.cdc.gov/emes/ALS/#conted.

"In addition to web-based modules for patients and caregivers teaching how to use the ATSDR CDC National ALS Registry," said Brooks, "there are valuable modules for physicians, nurses, and other providers regarding clinical aspects of ALS. We have used these modules to train participants in ALS clinics since the amount of knowledge gained in a short amount of time brings everyone up to par for disease-specific certification through The Joint Commission process of disease-specific certification."

For specific information about how your patients can enroll in the National ALS registry, visit www.cdc.gov/als.



Benjamin R. Brooks, MD