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**Background:**
Primary Lateral Sclerosis (PLS) is a neurodegenerative disease characterized by progressive Upper Motor Neuron (UMN) dysfunction of unknown etiology. There are approximately 1,000 people in the United States diagnosed with PLS, and the few case series that have previously been conducted only captured up to 50 patients per study. The aim of this study was to establish a retrospective longitudinal registry of patients with PLS seen at NEALS sites to better understand symptom burden, disease progression, and patterns of clinical management across NEALS sites.

**Methods:**
This study was a retrospective chart review to identify patients with PLS seen at a NEALS site between January 1, 2000 and December 31, 2015. Participating sites filled out a standardized data collection form for eligible PLS patients seen in their clinic. Patients were required to be 18 years or older and to have met Pringle Criteria for PLS diagnosis, including a symptom duration of at least 3 years. Patients with a family history of motor neuron disease or Hereditary Spastic Paraplegia (HSP) were not eligible for the study. Some data of interest included clinical characteristics, disease-related symptoms, medications for symptom management, use of assistive devices, and mortality or date of last contact.

**Results:**
This study included 250 patients seen at 21 NEALS sites (18 in the U.S., 2 in Israel and 1 in Canada). Preliminary results revealed an average age of onset of 53 years and an average duration between symptom onset and diagnosis of 6.5 years. The ratio of males to females was nearly 1:1. Ninety-six percent of patients were Caucasian. Only a minority of patients had gastrostomy tubes placed, used assistive ventilation, or died during the observation period.

**Conclusions:**
Analysis of the NEALS PLS Registry is ongoing. Data from the registry are expected to provide us with a better understanding of PLS natural history, clinical care and symptom management, and may help identify predictors of disease progression. Data from the NEALS PLS Registry may facilitate the development of studies focused on reducing disability and symptom burden in patients with PLS.

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