National Multiple Sclerosis Society

Support Establishing Disease Registries for Multiple Sclerosis and Parkinson's Disease

Request

On behalf of people living with multiple sclerosis (MS) nationwide, the National Multiple Sclerosis Society urges you to co-sponsor the **National MS and Parkinson's Disease Registry Act (H.R. #/S. #)**, which would establish separate Multiple Sclerosis and Parkinson's disease registries at the Agency for Toxic Substances and Disease Registry (ATSDR) in the Centers for Disease Control and Prevention (CDC).

Currently, a national coordinated system to collect and analyze data on MS or Parkinson's in the United States does not exist. Accurate knowledge and information about incidence and prevalence is critical to gain a better understanding of each of these diseases. These registries could help uncover and inform promising areas of MS and Parkinson's research such as genetic and environmental risk factors, and support the discovery of disease therapies, treatments, and one day a cure.

Position

The National MS Society, the Parkinson's Action Network, and activists nationwide support the establishment of permanent **national multiple sclerosis and Parkinson's disease registries to measure the incidence and prevalence of MS and Parkinson's in the United States.**

MS Registry

The MS Registry will serve as an important source of epidemiological information for researchers, health care providers, patients, and the broader MS community. Currently, no accurate estimates are available to help us better understand the complexities and intricacies of the MS population. The last national study of incidence and prevalence of MS was conducted in 1975. That lack of core knowledge inhibits MS research, programs, and services from progressing further.

The information collected through the MS Registry will provide a foundation for evaluating and understanding many MS factors such as geographic clusters of MS diagnoses, variances in the gender ratio, disease burden, and changes in health

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care practices. The resulting data could be used to provide consistency and coordination in addressing the disease nationwide.

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Supporting Rationale

- The legislation addresses economies of scale by using lessons learned in order to create pilot projects and ultimately a national registry for a variety of neurological diseases. The legislation establishes an Advisory Committee on Neurological Diseases National Surveillance Systems to examine launching registries for other neurological diseases and disorders.

- An accurate assessment is necessary to better understand the MS population in the United States. The MS Registry should, at a minimum, provide accurate information about the incidence and prevalence of MS for future planning of health care needs, detect changes in health practices, assess disease burden, promote advocacy, and support a wide range of research initiatives.

- While several small and uncoordinated MS registries and databases exist in the United States, one national harmonized data collection system does not exist to provide an accurate national overview. The National MS Society estimates the total number of people living with MS to be approximately 400,000 nationwide, but it is difficult to know the total number without a permanent, national system.

- In fiscal year 2006, ATSDR moved forward to develop a strategic plan for a national data collection system on MS that would provide these much needed incidence and prevalence estimates. The Agency conducted two pilot projects that evaluated the various data collection methodologies and the feasibility of establishing a nationwide system.

- It is anticipated that a national registry will involve mining several data sources and health information systems linked electronically. Data sources could include Medicare, Medicaid, private insurers, the Department of Veterans Affairs, NARCOMS, existing state registries, pharmacy databases, death certificates, physicians, and medical institutions.

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