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Testimony – Senate Subcommittee on Labor-HHS-Education and Related Agencies
Department of Health and Human Services

Thank you, Chairman Harkin and Ranking Member Moran, for allowing me to testify on behalf of the more than 2.2 million Americans living with epilepsy and their families, including my own. Specifically, I want to express my support for continued funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), as well as funding for epilepsy research at the National Institutes of Health.

Epilepsy is the nation's fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease; making it an important public health condition. Epilepsy is a complex spectrum of disorders—sometimes called the epilepsies—that affects millions of people in a variety of ways and is characterized by unpredictable seizures that differ in type, cause, and severity. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.

In October, 2012, the Epilepsy Foundation began a merger with the Epilepsy Therapy Project to create a unified organization driving education, awareness, support, and new therapies for people and families living with epilepsy. This merger became effective on January 1st and brings together the mission and assets of both organizations, including www.epilepsy.com, the leading portal for people, caregivers, and professionals dealing with epilepsy; 47 affiliated Epilepsy Foundations around the country dedicated to providing free programs and services to people living with epilepsy and their loved ones; scientific, professional, and business advisory boards comprised of leading epilepsy physicians, health care professionals and researchers, industry professionals, and investors with experience in clinical care, as well as in the evaluation and commercialization of new therapies; a track record of identifying and supporting important new science, translational research programs, and the most promising new therapies; and the Epilepsy Pipeline Conference, a leading global forum organized in partnership with the Epilepsy Study Consortium that showcases the most exciting new drugs, devices, and therapies.

The Epilepsy Foundation has long realized that epilepsy should be a priority for the federal public health system, and that public health programs can help build safer communities, end stigma and discrimination associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions. Stigma surrounding epilepsy continues to fuel discrimination and isolates people with epilepsy from the mainstream of life. Among older children and adults, epilepsy remains a formidable barrier to educational opportunities, employment, and personal fulfillment. There is a continuing need to better understand the public health impact of the condition, promote initiatives that encourage self-management, and improve mental health. Meeting these needs will help create an environment in which people will feel free to disclose their epilepsy or seizures without fear of discrimination or reprisal.

The Epilepsy Foundation was pleased to participate in the 2012 Institute of Medicine report: *Epilepsy Across the Spectrum: Promoting Health and Understanding*. We believe that many of the 13 recommendations from the report reinforce the need for public health programs that help people with epilepsy access the best care and the importance of a health care workforce that is educated about seizures and epilepsy.

The CDC is the lead federal agency for protecting the people's health and safety. It is responsible for providing credible information to enhance health decisions and for promoting health through strong partnerships. The 2012 Institute of Medicine report calls upon the CDC to continue and expand collaborative surveillance and data collection, and we strongly support this recommendation to improve epilepsy surveillance within the CDC. The report also calls on the CDC to work with the Epilepsy Foundation and its affiliates to enhance educational and community services for people with epilepsy.

The CDC epilepsy program focuses on better understanding the epidemiology and impacts of epilepsy, developing and bringing interventions to the public that improve quality of life for people with epilepsy, and working with partners to change systems and environments to better support those living with this neurological condition. CDC collaborates with partners to improve public awareness and promote education and communication at local and national levels. Programs focus on law enforcement and emergency medical responders, school-based students and staff, seniors, unemployed and underemployed adults, and underserved minorities living with epilepsy.

The Epilepsy Foundation strongly believes that not only should the CDC program maintain its current funding to continue the quality programs that help address care and eliminate stigma, but also that it should receive additional funding to fulfill the recommendations and the investment of the IOM report and take advantage of the research and guidance that the report provides.

HRSA directs national health programs that improve the Nation's health by assuring equitable access to comprehensive quality health care for all. HRSA promotes a community-based system of services mandated for all children with special health care needs; supports programs that are designed to break down barriers to community living for people with disabilities; and provides primary health care to medically underserved people. The 2012 Institute of Medicine report also calls upon stakeholders like the Foundation and HRSA to identify needs and improve community services for underserved populations. We believe that Project Access is an important part of meeting that goal and fully support the work of HRSA to empower families in health decision making, promote medical home models, support access to health care, increase early health care screenings, and facilitate transition for youth to improved healthy and independent lives.

Project Access is a national effort which involves state agencies, physicians and other health care providers, families, schools, and community resources to implement demonstration projects in medically underserved areas to improve health care outcomes and access for children with epilepsy. Demonstration projects have been conducted in California, Washington, D.C., Wisconsin, New Jersey, Mississippi, Illinois, West Virginia, Alaska, Nevada, Wyoming, Washington, New Hampshire, Maine, Florida, New York and Oregon. These projects not only serve needs of an important public health condition like epilepsy, but can serve as a model for other chronic health conditions and disabilities.

The Epilepsy Foundation understands the financial constraints facing our nation today. We encourage Congress to continue funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention and the Health Resources and Services Administration. We also urge Congress to not abandon research initiatives that have been partially funded at the National Institutes of Health, and to support funding for a cure and better treatments for epilepsy.

Thank you for your consideration of this critical issue.