Landmark IOM Report Shows 1 in 26 will have Epilepsy in Lifetime

Report calls for urgent action – across multiple dimensions – to improve the lives of people with epilepsy and their families.

WASHINGTON April 16, 2012 -- A landmark study from the Institute of Medicine (IOM) reports that your chance of developing epilepsy at some point in your life is one in 26. Onset is highest in children and older adults. But epilepsy knows no boundaries—it can strike at any age and across all socio-economic levels and ethnicities. There is no known cure and one-third of people with epilepsy have treatment-resistant or refractory epilepsy.

With more than 150,000 new epilepsy cases diagnosed in the U.S. annually, epilepsy is the fourth most prevalent neurological disorder after migraine, stroke and Alzheimer's disease. Despite being so common, epilepsy gets less public recognition than some neurological disorders that affect fewer people.

In introducing the report, IOM President Harvey Fineberg, M.D., Ph.D. described epilepsy as “a problem remarkably hidden for such a visible illness,” and later commented that the condition is “a very serious problem that has been too long neglected as a public health concern. We hope that this report will begin to change the way in which we as a nation come to understand, embrace, deal with and solve the problem of epilepsy.”

Alarmingly, the number of epilepsy cases is much higher than many people realize. Thus, the IOM report highlights the vast need for better surveillance and data collection, including through electronic health records, to more precisely define the scope of the problem. “Current data sources provide a patchwork of surveillance activity,” it says, “and substantially limit the ability to understand, plan and guide the provision of policies.”

“Epilepsy’s high rate of occurrence and heavy burden on patients and families is in stark contrast with the highly insufficient attention the disease gets at all levels of our health care system and our society at large,” says Frances Jensen, M.D., president of the American Epilepsy Society and chair of Vision 20/20, a cooperative group of more than 20 consumer, health professional, and advocacy organizations concerned with the broad spectrum of the epilepsies. “Gaps in the nation’s ability to deal with epilepsy and its consequences prevail in so many spheres that vigorous action is urgently needed to affect change and create a system that will assure accessible, comprehensive, high-quality optimal care for every person who has the condition.”
Epilepsy is a spectrum of more than 25 seizure syndromes—sometimes called the epilepsies—that affects more than 2.2 million Americans in a variety of ways. The disorder is characterized by unpredictable seizures in which the brain produces sudden bursts of electrical energy that can interfere with a person’s consciousness, movements and sensations. Seizures differ widely in type, cause, severity, and treatment.

The impact that epilepsy has on physical health and quality of life spans another spectrum, with individuals experiencing different health outcomes. In addition, people with epilepsy often experience quality of life issues, including but not limited to impaired memory and cognitive functions, difficulty in social interactions and achieving gainful employment, and driving restrictions.

Access to care varies with significant disparities along racial, ethnic, and socioeconomic lines in diagnosis and treatment of patients. A significant challenge for people with epilepsy, according to the IOM report, has been the way epilepsy is misunderstood and misperceived, leading to the perpetuation of age-old stigma.

The report further underscores that epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole, with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy-related deaths. Estimates in the report indicate that 2-10 years of life are lost for people who have epilepsy.

Given the current gaps in epilepsy knowledge, care and education, the IOM report emphasizes the urgent need to take action—across multiple dimensions—to improve and save lives. The IOM report provides the research priorities and action-oriented steps needed to enable short- and long-term improvements for people with epilepsy.

“This new report will serve as a roadmap for real progress in the next few years to improve the lives of individuals with epilepsy, increase access to medical care and social services, increase public awareness, reduce stigma, and work towards better education of healthcare professionals around epilepsy care and research,” adds Jensen.

**About Vision 20/20** -- Vision 20/20 is a cooperative group of more than 20 consumer, health professional, and advocacy organizations concerned with the broad spectrum of seizure syndromes and disorders known as the epilepsies. The group’s primary interests are improving epilepsy awareness and understanding, and advancing basic and clinical research to prevent, treat, and cure this serious medical condition. Vision 20/20 members provided public testimony before the Institute of Medicine’s independent Committee on “The Public Health Dimension of the Epilepsies”.

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