Epilepsy Community Collaborates on Web-Based Tool to Improve Access to Specialized Care

Washington, D.C., December 8, 2013 – Receiving specialized care in a timely manner plays a significant role in the progression and impact of epilepsy on someone’s life. Multiple organizations across the global epilepsy community have collaborated on “My Seizure, Know More” a web-based tool that empowers people with epilepsy and their families to seek specialized care.

Following the release of the Institute of Medicine Report: Epilepsy across the Spectrum—Promoting Health and Understanding (2012), representatives of Vision 20/20, a collaborative effort of epilepsy organizations, began working on a web-based tool to help individuals with epilepsy, their families, and caregivers determine their need for specialized epilepsy care. The tool, found at www.MySeizuresKnowMore.com, is made up of 6 simple questions that are essential to epilepsy diagnosis and management. The tool provides information and resources related to seizure control, psychological, social, and behavioral concerns and other comorbidities that can impact health and quality of life. “My Seizure, Know More” allows individuals to print or email a report with their responses and encourages them to share it with their current health care providers to determine if a change in their treatment plan is needed or if a referral to an epilepsy specialist or center would be beneficial.

For many of the 2.2 million Americans living with epilepsy, their seizures are well-controlled with medications and other treatment options. Unfortunately, for about thirty percent of Americans with epilepsy, their seizures persist or become refractory and are often more complicated to diagnose and treat effectively. People with persistent seizures may get worse over time; have higher rates of depression, anxiety, injuries, other health problems and even death. Early referral to specialized epilepsy care would benefit these individuals greatly. Yet, the IOM report highlights that on average it takes more than 15 years for individuals with refractory epilepsy to be seen at a specialized epilepsy center. The goal of “My Seizure, Know More” is to reach individuals with active seizures as early as possible and to get them the specialized care they need.

“As a parent of a child with intractable epilepsy and Tuberous Sclerosis Complex, my wife and I constantly struggle with understanding the impact of our son’s seizures on his health and cognitive development,” explained Robert Moss, Founder of SeizureTracker.com and member
of the working group developing the tool. “With the complexity and individualized care needed for a neurological condition like epilepsy, successful advocacy for our son relies on seeking out specialized physicians and asking the right questions.”

For more information on the Epilepsy Tool, including how to put the tool on a website – go to www.MySeizuresKnowMore.com.

**Vision 20/20** is a consortium of over 30 epilepsy organizations working together on research, outreach, education, and access to specialized epilepsy care along with other issues of interest and importance to people living with epilepsy and their families.