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Epilepsy Patients Caught in Treatment Gap are Not Accessing State-of-the-Art Care

First ever global consensus on refractory epilepsy to aid better care

Boston, December 4, 2009 -- According to Steven C. Schachter, M.D., president of the American Epilepsy Society (AES), despite significant progress in diagnosing and treating epilepsy, there is still an enormous gap between what is currently being done and what is possible today to lessen the burden of epilepsy around the world. The consequences are significant, as uncontrolled epilepsy leads to a diminished quality of life, and a greater risk of disability and death.

Citing data from the World Health Organization (WHO), Dr. Schachter said, "There are some regions of the world where up to 90 percent of people with epilepsy are on no treatment whatsoever. That is a staggering statistic." He also noted that, "Epilepsy is more than seizures," citing the effect epilepsy has on quality of life. People with epilepsy often suffer from depression, anxiety and discrimination. He also pointed to racial, ethnic and socioeconomic disparities in access to treatment—surgery in particular—and significant under-diagnosis and treatment of associated complications of mood, memory and cognition.

R. Edward Hogan, M.D., of the Washington University of St. Louis, Patrick Kwan, M.D., Ph.D., of the Chinese University of Hong Kong and Eric R. Hargis, president and CEO of the Epilepsy Foundation, joined Dr. Schachter to address the treatment gap in epilepsy at the American Epilepsy Society 63rd Annual Meeting today. Dr. Kwan participated in an international committee of epilepsy experts that developed the first global consensus definition of refractory epilepsy. The newly developed definition will be presented during a symposium on Tuesday.

Dr. Kwan said, "The new consensus definition represents, for the first time, a common language in recognizing refractory epilepsy that can be applied by clinicians at all health care levels. We believe its general adoption into clinical practice can have a significant impact in improving patient care, by providing clinicians a framework to recognize and promptly refer patients with refractory epilepsy to specialist centers for further assessment and management."

Researchers in another study to be reported here have found there continues to be a major gap—averaging 17 years—between the diagnosis of epilepsy and pre-surgical evaluation at a specialized epilepsy center in the U.S. Professional guidelines recommend that patients should be evaluated as potential surgery candidates after appropriate trials (typically less than 2 years) of first-line antiepileptic drugs have failed.

"Even with the plethora of epilepsy therapies now available," Dr. Schachter said, "the CDC estimates that at least 45 percent of people with epilepsy here in the U.S. continue to experience seizures. Complete freedom from seizures is not a possibility for everyone who has epilepsy. But it is important for patients with continuing seizures and their health care providers to make every effort toward that goal."

In order for patients to receive optimal care, the panel agreed, there must be a mutual effort between physicians and empowered patients. Eric Hargis said people with epilepsy often face structural barriers to health care, such as access

to insurance and the cost of medical care, but they are also impacted by attitudinal barriers. A number of recent studies, including research supported by the Epilepsy Foundation, show that mood disorders and medication side effects impact the quality of life of patients more than the frequency or severity of their seizures. However, despite debilitating side effects, people were reluctant to seek better treatment options or even talk to their physicians about what they were experiencing. Hargis referred to it as a tendency to believe that “this is as good as it gets.” He said, “If your doctor says, ‘this is as good as it gets,’ it’s time for a new doctor.”

The heavy toll that undiagnosed, untreated and sub-optimally treated epilepsy imposes on the millions of people with epilepsy in the U.S. and around the globe has led the World Health Organization to raise the international campaign against the disorder to the highest level within its organization. Closing the wide gap in treatment will require major efforts on the part of governments, health care communities, researchers and affected individuals and families everywhere. But, with people's lives at stake, the epilepsy representatives say, there is no other course.

For more information on seeking better treatment options, in an accessible, easy-to-understand format, visit www.nomoreseizures.org. Follow [epilepsyUSA's blog](#) covering the AES annual meeting.