

## American Epilepsy Society Position on Access to Epilepsy Care

Within the context of the evolving healthcare reform legislation, we, as epilepsy care specialists, would like to define the needs of our patient population, and be proactive in assuring that their needs be adequately met. Benefits forthcoming as a result of the legislation must include:

- Extending coverage to currently uninsured Americans
- Outlawing denial of coverage due to pre-existing conditions (i.e., epilepsy)
- Eliminating lifetime limits on health coverage

Additionally, extension of benefits to include the specialized care essential for this vulnerable population living with epilepsy is essential.

Epilepsy is one of the most common neurological disorders. Roughly, 10% of people in the U.S. will have a seizure during their lifetime and ~ 1% (2.5 million) of the population has active epilepsy. Most people with epilepsy (PWE) are able to lead normal and productive lives if appropriate care is accessible. With adequate care, up to 70% of PWE can become seizure-free. Accessing quality care early in the course of epilepsy can lead to substantial health benefits and healthcare cost savings.

It has been reported that up to 70% of medically refractory epilepsy patients who are eligible for epilepsy surgery can achieve seizure freedom with surgery (Wiebe S, et al, 2001), while less than 10% will become seizure free after two medication trials (Kwan and Brodie, 2006). For those who are not eligible for surgery, implanted electronic devices may sometimes offer substantial improvement. For children with uncontrolled epilepsy, dietary treatment (usually with the ketogenic diet) may be useful. These advanced therapies are often only available through specialized epilepsy centers and require advanced diagnostic testing and evaluations by experienced multidisciplinary care teams. Additionally, these multidisciplinary teams can provide the necessary education, problem solving, and behavioral strategies for patients and family members to manage the seizures as well as the associated effects that seizures have on everyday life.

For those PWE who are not seizure-free with medications, decreasing seizures and medication side effects through subspecialty care may improve quality of life and restore productivity. Uncontrolled seizures also places PWE at risk for multiple co-morbidities, frequent emergency room visits, hospitalizations, therapies that might not otherwise be needed, and increased mortality (Nashef L, Ryvlin P, 2009; So EL, 2006). It is critical that PWE have access to the specialty care they need regardless of the final structure of healthcare reform.

The American Epilepsy Society is the organization of healthcare professionals who are committed to the highest level of care for patients with epilepsy. These health care professionals usually work in comprehensive epilepsy centers. They have expertise with established and emerging medical and surgical therapies. In addition, they have training in and access to diagnostic and therapeutic technologies that are not otherwise available.

Epilepsy specialists agree that PWE must have access to and insurance coverage for all antiepileptic medications in all their formulations without formulary restrictions. For each antiepileptic medication prescribed, continuity of supply from the same manufacturer is essential for many patients with epilepsy to preserve consistent efficacy, avoid toxicity, and diminish concern over a change in their medication.

Epilepsy specialists agree that PWE must have access to and insurance coverage for appropriate diagnostic testing. Diagnostic testing (Advanced neuroimaging and electroencephalography (EEG), long-term video EEG monitoring, neuropsychological testing) at subspecialty centers is often a critical step in optimizing the treatment of epilepsy.

Epilepsy specialists agree that patients with epilepsy should have access to and insurance coverage for more aggressive therapeutic strategies (neurosurgery, implanted electronic devices, dietary therapy, and therapies in development) in cases where medications have failed to yield optimal seizure control.

Epilepsy specialists agree with the implementation of upcoming benefits of recent healthcare reform legislation, including extending coverage to currently uninsured Americans, outlawing denial of coverage because of the pre-existing condition of epilepsy, and eliminating lifetime limits on health coverage.

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## References

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2. So EL. Demystifying sudden unexplained death in epilepsy--are we close? *Epilepsia*. 2006;47 Suppl 1:87-92.
3. Nashef L, Ryvlin P. Sudden unexpected death in epilepsy (SUDEP): update and reflections. *Neurol Clin*. 2009 Nov;27(4):1063-74.
4. Kwan , Brodie M. Refractory Epilepsy: Mechanisms and Solutions, Expert review in therapeutics, Mar 6(3); 397- 406.

Drafted by the AES Practice Management Committee Health Care Reform Workgroup

The American Epilepsy Society, is the leading organization of clinical and research professionals working to advance and improve the treatment of epilepsy through the promotion of research and education for healthcare professionals. Society membership includes epileptologists and other medical professionals, allied healthcare professionals, and scientists concerned with the care of people who have seizure disorders.