In Senate Health Committee  S. 67 (HOYLMAN)
Passed Assembly  A. 3298 (EPSTEIN)

AN ACT to amend the public health law, in relation to information provided to patients regarding sudden unexpected death in epilepsy

The bill would require health care practitioners to provide patients with epilepsy with current and evidence-based information about Sudden Unexpected Death in Epilepsy (SUDEP) risk factors and conditions, as well as contact information for nonprofit organizations that provide support services for epilepsy conditions. The Medical Society of the State of New York is opposed to this measure.

The bill would require health care practitioners to provide patients with epilepsy with current and evidence-based information about Sudden Unexpected Death in Epilepsy (SUDEP) risk factors and conditions, as well as contact information for nonprofit organizations that provide support services for epilepsy conditions. While we appreciate the intent of this measure, the Medical Society of the State of New York is opposed to this measure.

According to the Centers for Disease Control and Prevention, Sudden Unexpected Death in Epilepsy (SUDEP) refers to deaths in people with epilepsy that are not caused by injury, drowning or other known causes. Studies have suggested that they are extremely rare. According to neurological experts, a SUDEP case usually occurs during or immediately after a seizure and the exact cause is unknown. The main risk factors for SUDEP are uncontrolled or frequent seizures and generalized convulsive (tonic-clonic or grand mal) seizures. The most important step to reduce the risk of SUDEP is for patients to take their seizure medicine as prescribed and if seizures continue to consider seeing an epilepsy specialist. Other possible steps to reduce the risk of SUDEP include: avoiding drinking too much, getting enough sleep, avoiding seizure triggers, and training adults in the house in seizure first aid.

The Medical Society of the State of New York appreciates that the sponsors of this measure have narrowed the provisions from earlier versions of the bill. However, this measure continues to the put the physicians’ license at risk for failing to give a form to a patient. While there is nothing problematic in and of itself with providing a standardized pamphlet (that will have to be continuously updated), physicians already have every incentive to ensure their patient receives the proper treatment to manage this condition. We should be ensuring patients have access to the best neurological treatment, not taking steps that could potentially drive some neurologists away from treating epileptic patients or patients who could be suffering from epilepsy.

For all the reasons above, the Medical Society of the State of New York opposes this measure and urges it defeat.

Respectfully submitted,
Pfc/oppose
2/5/2021