April 22, 2014

The American Epilepsy Society (AES) is the leading organization of clinical and research professionals specializing in the treatment of epilepsy -- a common neurological disease affecting 1 in 26 people at some point in their lifetime. Today more than three million Americans, including almost 400,000 children, live with epilepsy, with one-third living with treatment-resistant seizures.

The recent anecdotal reports of positive effects of the marijuana derivative cannabidiol (CBD) for some individuals with treatment-resistant epilepsy give reason for hope. However, we only have anecdotal reports and robust scientific evidence for the use of marijuana is lacking. Of great concern is that the children who have reportedly responded to CBD are those with especially medication resistant seizures, often occurring hundreds of times per week. AES supports the development of well-controlled research studies of any potential new treatments for this disease.

A significant barrier to obtaining this scientific evidence for CBD is that marijuana is currently classified by federal law as a Schedule I drug. This makes it very difficult for researchers to gain access to marijuana, or any chemical found in it. Acquiring the permissions necessary to do marijuana research can take years and require an enormous burden of paperwork. These research impediments are hindering scientific advancement and this lack of research is impacting the care of people with epilepsy, especially children.

AES believes that there must be more research done on CBD-rich marijuana. Yet, Schedule 1 implies there is “no currently accepted medical use,” however available research shows that marijuana and its derivatives can be effective in disorders like spasticity in multiple sclerosis. We believe that to foster timely research, the DEA must change the compounds derived from marijuana from Schedule I to a less restrictive category. The time is right for DEA to act.

While access to marijuana for medical use is occurring on a state-by-state basis, federal policies that govern researchers remain unchanged. We stand at an unusual point where epilepsy families are demanding access to a substance that may or may not be beneficial; the medical and scientific community lacks necessary efficacy and safety data to make treatment decisions for people with
epilepsy, especially in children; and the Drug Enforcement Agency’s restrictive scheduling of marijuana hamstrings research. A change in marijuana’s Schedule I status will help enable the necessary research to be done.

The use of marijuana by children living with epilepsy will continue to grow, as more states approve legalization and compassionate use legislation. The developing patchwork system is encouraging families of children with severe epilepsy to move across state lines in search of marijuana, an untested treatment. This also results in a situation where clinicians are being asked to care for these children with no protocols or practice guidelines.

The Drug Enforcement Agency is in a unique position to allow research to advance. If the harmful aspects of marijuana outweigh the therapeutic benefits, we need to find out now, before more children have tried and used marijuana. If there are components of cannabis with specific therapeutic values we need to know this and we need to develop drugs that utilize these components to help the nearly one million people living with drug resistant epilepsy.

The Board of Directors of the American Epilepsy Society urges the DEA to change the current Schedule I classification of marijuana as soon as possible to enable epilepsy researchers to do the research necessary to determine the safety and efficacy of marijuana and its derivatives as a treatment for epilepsy in a timely manner.

Our community is ready to work with you to develop the research studies once you have changed the scheduling of marijuana. If you have any questions regarding this letter, we kindly ask that you reach out to me directly or to Eileen Murray, executive director at 773-552-4714.

Sincerely,

Elson So, M.D.
President