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Ms. Donna Pickett
Co-Chair, ICD-10-CM Coordination and Maintenance Committee
National Center for Health Statistics
ICD-10-CM Coordination and Maintenance Committee
3311 Toledo Road
Hyattsville, Maryland 20782

RE: ICD-10 Code for Dravet Syndrome

Dear Ms. Pickett:

On behalf of the American Epilepsy Society (AES) I am writing to support the Dravet Syndrome Foundation proposal to create a new code for Dravet Syndrome (DS). Founded in 1946, the American Epilepsy Society (AES) is a medical and scientific society whose members are dedicated to advancing research and education for preventing, treating and curing epilepsy.

Dravet Syndrome is a genetic encephalopathy that presents in the first year of life. It is an uncommon disorder that represents about 7% of all severe epilepsies starting before the age of 3 years. Currently, there is no unique ICD code to identify patients with DS. In ICD-10-CM, Dravet syndrome is currently being reported inconsistently. Dravet Syndrome has a unique and distinctive phenotypic spectrum and AES shares the view that it is important to differentiate properly identify and code DS. While SCN1A mutations are often seen in children with DS, not all children with SCN1A mutations have an encephalopathy /DS, and not all children with the Dravet phenotype harbor a SCN1A mutation.

Specific ICD codes for DS are important for ensuring appropriate and safe treatment as DS has specific pharmacological sensitivities and prognosis. Effective ICD coding also contributes to effective clinical research. Specific ICD codes are essential to be able to better identify patients with DS, measure outcomes, and understand the epidemiology of the disease, and to help direct treatment.

For these reasons, AES supports establishment of the proposed new code to identify this condition for research and reporting, and also supports the broader need to align ICD10 codes with other epileptic encephalopathies and genetic disorders from a neurologic and epilepsy perspective to keep pace with continuing advances in gene discovery and modifications in clinical phenotyping of the pediatric epilepsies.

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Thank you for the opportunity to comment on the proposed ICD-10-CM codes for Dravet Syndrome and epileptic encephalopathies. Please feel free to contact me with questions.

Sincerely,



Shlomo Shinnar, MD, PhD
President
American Epilepsy Society



Tim Welty, M.A., Pharm.D, FCCP
Council on Clinical Activities
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Cc:

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