

May 2, 2014

Ms. Carolyn W. Colvin, Acting Commissioner
Office of Regulations and Reports Clearance
Social Security Administration
107 Altmeyer Building
6401 Security Boulevard
Baltimore, MD 21235-6401

RE: SSA-2006-0140

Dear Acting Commissioner Colvin:

The Epilepsy Foundation appreciates the opportunity to offer comments to the Social Security Administration (SSA) on the proposed revised medical criteria for evaluating disability claims involving neurological disorders for adults and children. We support the comments submitted by the American Academy of Neurology and the American Epilepsy Society, and have also prepared comments on behalf of the Foundation.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 2.8 million Americans with epilepsy and seizures. We foster the well-being of children and adults affected by seizures through research programs, educational activities, advocacy and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime, and many of them are living with one or multiple disabilities.

We believe it is imperative that disability determinations and decisions be made in accordance with current advances in medical knowledge and treatment in order to evaluate neurological disorders appropriately. The Epilepsy Foundation has reviewed the Revised Medical Criteria for Evaluating Neurological Disorders proposed rule published in the *Federal Register* on February 25, 2014 and offers the following comments.

11.00H1(adults), 111.00F1 (children): Definition of epilepsy

Epilepsy is surprisingly common, but is often poorly understood and misdiagnosed which can lead to significant variations in treatment. Of the more than 2.8 million Americans that are living with epilepsy, roughly 30 percent have medically intractable seizures. Deficits in quality of life due to epilepsy and its treatment are comparable to conditions such as diabetes, heart disease and depression.

In this proposed rule, SSA defines epilepsy as generalized tonic-clonic (GTC) and dyscognitive seizures in adults, and as GTC, dyscognitive and absence seizures in children. We believe that a more accurate definition of epilepsy should also include simple partial seizures (motor), refractory drop attacks, and refractory absence seizures because individuals with these types of seizures have the same impairment of consciousness, and the seizures are just as disabling, as GTC or partial onset seizures. We would also like to stress that the term "dyscognitive seizure" has been proposed by the International League Against Epilepsy to define focal seizures where alteration of cognition is the major feature, but it has not been completely accepted. The Epilepsy Foundation suggests that SSA should either use the current term "complex partial" or should only use the term "dyscognitive" with an explanation stating this seizure type as "focal seizures with or without alteration of awareness (dyscognitive features)". This is explanatory, accurate, and will capture the term "dyscognitive" if it is wholly adopted in the future.

11.00H4 (adults), 111.00F4 (children): Counting seizures

The Epilepsy Foundation disagrees with SSA's proposal to count multiple seizures occurring within a 24-hour period as one seizure; and count status epilepticus as one seizure. We do not believe that listing status epilepticus as a single seizure is a balanced approach because multiple seizures and status epilepticus are much more extreme conditions than a single seizure and, thus, listing them as such does not fully describe/capture the severity of the event. Instead, we suggest that status be considered "extreme" following the categorization of motor dysfunction. Sequelae of status epilepticus can be long lasting or permanent. Many patients who have multiple bouts of status epilepticus become disabled on cognitive grounds.

In addition, the disabling effect of seizure frequency depends on many factors including ictal behavior, physical trauma due to events, life style, and seizure duration. For example, one seizure every three months in Minnesota precludes driving a car which is very disabling in rural parts of the state. In this scenario, one seizure/month is disabling. Therefore, the Epilepsy Foundation recommends that the SSA change the seizure frequency requirement to at least one seizure a month for epilepsy. We understand that counting seizures is nuanced, and that seizure burden must account for both number and severity that would prevent the individual from performing activities of daily living, physical functioning, maintaining social functioning, completing tasks in a timely manner, and/or his or her occupation.

The Epilepsy Foundation appreciates the opportunity to provide comments on this proposed rule. Please do not hesitate to contact Angela Ostrom, Vice President of Public Policy and Advocacy, at 301-918-3766 or aostrom@efa.org, with any questions or concerns.

Sincerely,



Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation