



January 11, 2017

Donald Trump  
President-elect of the United States of America  
Presidential Transition Office  
1800 F Street, NW  
Washington, DC 20006

Dear President-elect Trump,

The Epilepsy Foundation would like to express our continued commitment to the successful implementation of the Patient Protection and Affordable Care Act (ACA). Repealing the provisions of the ACA that are currently being proposed for repeal in Congress will send our health care system into disarray and lead to even more unaffordable and inaccessible health care for millions.

We strongly oppose repeal efforts that will again leave people living with epilepsy with enormous challenges in obtaining health care. The ACA allowed millions of individuals – many who had been unable to access health insurance in the past because of denials and exclusions for pre-existing conditions, as well as unaffordable premiums – to gain meaningful access to quality and affordable care. The Epilepsy Foundation leadership and public policy team would be interested in meeting with you and your health policy staff to discuss the needs of the epilepsy community.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than three million Americans with epilepsy and seizures. 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.

The historic health care reform law has helped to improve access to medical care and to appropriate treatments, and this improved access has had a dramatic impact on the health, family and employment situation of individuals living with epilepsy and seizures. Key aspects of the ACA have been significantly beneficial to those living with epilepsy and these must be preserved and/or strengthened.

**All pre-existing conditions and chronic illness must be covered without limitation.**

The elimination of discrimination in health insurance eligibility, renewal and pricing based on health status is vital to health care access for people with epilepsy. These provisions improved access to quality health care for people with epilepsy who were uninsured or under-insured including those who age-out of their parents' insurance and young adults and others who may have lost insurance when unemployed.

The Epilepsy Foundation supports the following provisions in the ACA to ensure health insurance is accessible to those in our community:

1. Insurers may not deny coverage for pre-existing conditions.
2. Discrimination based on an individual's medical history is prohibited for coverage renewal.
3. Plans may not base cost on an individual's medical history or condition.

**People with epilepsy must have access to and coverage for the care and treatment that works best for them.**

The Epilepsy Foundation believes that discrimination can occur in plans that do not offer adequate prescription drug formularies for epilepsy medications, fail to provide a robust network of neurologists that will serve patients in the plan's coverage network, or put the costs for such treatment or providers at a much higher rate than other conditions or treatments. We have urged the federal agency responsible for implementing the ACA to monitor insurance plans and processes to ensure that plans and benefit packages are not discriminatory to individuals with epilepsy or other chronic conditions or disabilities.

**Full access to health care cannot be achieved without considerations of affordability of coverage, co-pays and out-of-pocket costs for consumers.**

The Epilepsy Foundation believes it is critical to acknowledge the impact of rising costs of health care and prescription drugs. Cost can significantly impact the ability for people with epilepsy to fill prescriptions and/or see physicians; however, we know these activities are necessary for successful management of the condition. People with chronic illnesses are continuing to face increasing burdens from out-of-pocket costs. For these individuals who often manage a chronic health condition in addition to other health problems like heart disease, mental health issues, high blood pressure or high cholesterol, numerous co-pays can add up to such a level that they choose between their health and their living expenses. Without access to care, consequences are devastating for both the individuals and for the overall health care system – deteriorating health leads to higher health care costs.

The Epilepsy Foundation supports the following provisions in the ACA that provide economic relief for health care consumers:

1. No charge (or minimal allowable charge) for preventative care.
2. Cap on out-of-pocket expenses (including deductibles, copays and medication expenses).
3. No lifetime caps or annual limits on value of insurance benefits for enrollees.

**People with epilepsy who rely on the Medicare Part D prescription drug benefits need relief from expenses under the "donut hole."**

Traditionally, under most Medicare Part D drug plans, after a beneficiary has spent a certain amount of money and/or received a certain level of benefits, their coverage changes and they are responsible for all costs of drugs up to a certain level. This "gap" is sometimes called the "donut

hole." This lack of coverage and burden of paying 100 percent of drug costs during the donut hole period is very costly. For people with epilepsy who are on Medicare, this coverage gap endangers their access to treatment and efforts to maintain seizure control.

The Epilepsy Foundation supports the elimination of the Part D prescription drug coverage gap, which is being phased out under the ACA.

To close, we note that throughout implementation of the ACA, the Epilepsy Foundation has remained active in ensuring that new enrollees of health insurance, especially those with chronic health conditions, are not still facing barriers to care, including discriminatory benefit designs that limit access, such as restrictive formularies and inadequate provider networks; high cost-sharing; and a lack of plan transparency that may deprive consumers of information that is essential to making informed enrollment choices. We will continue to remain vigilant while strongly supporting the many advancements to our health care system included in the ACA.

Please do not hesitate to contact Angela Ostrom, Chief Legal Officer and Vice President Public Policy at our national office at 301-918-3766 or [aostrom@efa.org](mailto:aostrom@efa.org) with any questions or for further details.

Sincerely,

A handwritten signature in black ink that reads "Philip M. Gattone". The signature is written in a cursive style with a large, stylized "P" and "G".

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