Dear Chairman Alexander and Ranking Member Murray:

The Epilepsy Foundation appreciates the opportunity to provide input on the draft of the Lowering Health Care Costs Act of 2019.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the 3.4 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.

As individuals living with a chronic condition, people with epilepsy have frequent contact with the health care system. For the majority of people living with epilepsy, epilepsy medications are the most common and most cost-effective treatment for controlling and/or reducing seizures. However, people with epilepsy also need access to primary, preventive, acute, and emergency health care. Our comments will focus on access to prescription drugs, as well as other aspects of the health care system that impact people with epilepsy, including surprise medical billing and price transparency.

**Title I: Surprise Medical Billing**

We support the effort to address surprise medical billing, especially as it relates to emergency care and out-of-network care received at an in-network facility. People with epilepsy or experiencing seizures can end up in an emergency room under a variety of scenarios. It may be the first time someone experiences a seizure and not knowing what is happening, s/he goes to the emergency room for medical consultation and care. Or, seizures can render someone unconscious or cognitively impaired—whereby s/he is taken to the emergency room by loved ones or even strangers witnessing the seizure(s). Or, someone can enter status epilepticus whereby his/her seizure lasts longer than five minutes or the seizures are happening so frequently that the individual does not have time to recover between—necessitating emergency room care. Regardless of the situation, epilepsy and seizures can be life threatening, so it is crucial that people can access the medical care they need and are protected financially against surprise billing for emergency and out of network care. We support the approach taken in the draft bill. We agree that patients should only be held responsible for typical in-network cost sharing for
out-of-network emergency care and by out-of-network providers and that their cost sharing should count towards their deductible and out-of-pocket maximum. We also agree that patients should be protected from surprise billing for care provided inpatient following the emergency, unless the patient has been stabilized, given an estimate of their out of pocket costs, given a list of in-network facilities, and agrees in writing to continue to receive out of network care.

**Title II: Reducing the Prices of Prescription Drugs**

For the majority of people living with epilepsy, epilepsy medications are the most common and most cost-effective treatment for controlling and/or reducing seizures. Most people with epilepsy rely on prescription drug treatment(s) every day to reduce or control their seizures, work, raise their families, and participate in their communities. For people living with epilepsy and seizures, there is no “one size fits all” anticonvulsant, and the response to anticonvulsants can differ between seizure type and be different from person to person. Maintaining seizure control with minimal side effects on the correct anticonvulsant(s) requires careful evaluation and monitoring by healthcare providers and patient. Because it is such an individualized and complex condition, having *more* treatment options and having access to the *full range* of approved treatment options so that each individual with direction from his/her healthcare provider can identify and remain on the anticonvulsant(s) that works is vital.

The high cost of prescription medications, and the resulting high cost sharing and other restrictions on access like prior authorization and step therapy, however, are of significant concern to the epilepsy community and the Epilepsy Foundation. Twenty-one percent of adults with epilepsy reported not being able to afford prescription medications within the last year.¹ And prescription drugs are of course just one part of the significant healthcare expenditures that someone with a complex, chronic condition like epilepsy face. A 2015 review of published research found that average annual total direct healthcare costs for a person living with epilepsy can be up to $47,862 in 2013 dollars. Epilepsy-specific costs can be up to $19,749.²

We support efforts to encourage more generics into the market, including the proposals outlined in the discussion draft that address actions that currently may prevent the timely access to generics. However, bringing generic medications to market is not a panacea of the high cost of prescription drugs. “Generic” unfortunately does not always yield affordability and as described below, other barriers can be put in place, so we encourage the committee to consider additional reforms to ensure that efforts to reduce the price of drugs results in greater, not less, patient access.

In the epilepsy space, bringing generics to market does not always result in lower patient cost sharing or greater access. For example, when a generic form of Clonazepam (brand name Onfi)

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was introduced last year, many patients with commercial insurance reported higher cost sharing and stricter prior authorization requirements for both the brand and generic than had been in place when only the brand name drug was on the market. These reports are anecdotal, but represent a trend in the epilepsy space: bringing new generics on to the market does not always result in lower cost sharing or greater access for patients. Due to the opacity of the drug supply chain and private negotiations between issuers, pharmacy benefit managers, and prescription drug manufacturers, we have not been able to determine why bringing generics to market has not resulted in lower cost sharing. We believe that efforts to address the high list price of all drugs (brand and generic) should flow through to consumers in the form of lower cost sharing. We strongly support increasing access to generics to increase patient options, but encourage the committee to explore why bringing generics to market may not result in lower patient costs or easier access.

Title III: Improving Transparency in Health Care

Gag Clauses
We support efforts to increase transparency in health care services, including removing gag clauses that prevent issuers from providing cost and quality information to enrollees. Too often, enrollees experience their cost sharing as a surprise. If cost sharing is meant to encourage people to “shop” for health care or prioritize their care, the existence of surprise billing and surprise cost sharing shows that the system is not working. The opacity of health care prices and quality measures makes patient navigation of their cost sharing obligations impossible, and health care consumers may simply consume less care, even necessary and preventive health care. As mentioned, this can be life threatening for people with epilepsy. As cost sharing increases, we support efforts to help enrollees predict, and possibly lower, their out-of-pocket costs with pricing information.

To this end, we support the provisions to remove gag clauses that prevent plans from sharing cost or quality information with enrollees. We have supported similar proposals in the past that ensure clinicians, including pharmacists, can share cost information, including when an enrollee would face lower cost sharing without using their insurance.

However, such transparency is not a substitute for consumer protections against high cost sharing. While we support these efforts as a way to help people predict their out-of-pocket costs, we are still very concerned that cost sharing is simply too high. High cost sharing encourages patients to forego necessary care, which results in higher health care costs in the long run. We encourage the committee to explore limits on cost sharing in order to promote improved utilization of necessary and preventive health care.

Transparency Organization
The opacity of health care costs makes it difficult for people with epilepsy to navigate the health care system, predict their out-of-pocket costs, and afford their health care. We support the committee’s efforts to improve the transparency of health care spending and costs through the designation of a nongovernmental nonprofit organization to facilitate research on health care costs.
People with chronic conditions and disabilities like epilepsy are in frequent contact with the health care system and are impacted most by reforms to that system. While we support the facilitation of population-level research through this transparency organization, we are concerned that population-level research may not capture outcomes important to people with disabilities or chronic conditions, or may mask outcomes and quality issues that have a specific impact on people with disabilities or chronic conditions. To address this, we recommend that the committee add requirements for data to be disaggregated by chronic condition or disability to ensure that research is conducted in a manner that takes into account patient-reported outcomes and measures of quality and outcomes that matter most to people with disabilities and chronic conditions. Such disaggregation by race & ethnicity may also be useful for researching health disparities.

To further promote the research of patient-centered and disability-competent outcomes, we encourage the committee to require the inclusion of people living with chronic conditions and disabilities and chronic condition and disability advocacy organizations in the advisory committee.

**Provider Directories**

We support the proposed requirements for the provision of up-to-date provider directories. We also strongly support the proposal to not apply out-of-network cost sharing for an enrollee who seeks care based on an out-of-date provider directory. With regard to the information included in the provider directory, we encourage the committee to consider including non-English language spoken by the provider and information on the physical accessibility of the office, specifically the accessibility of medical diagnostic equipment that meets the specifications of the U.S. Access Board found at: 36 CFR 1195 and [https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards/text-of-the-proposed-standards-8](https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards/text-of-the-proposed-standards-8).

**Pharmacy Benefit Managers**

As we have noted above, the opacity of the drug supply chain and negotiations between issuers and pharmacy benefit managers make it difficult for patients to estimate their out-of-pocket costs, learn why costs may have changed, and navigate their benefits. For these reasons, we support the efforts to increase transparency of pharmacy benefit manager data and activities.

In addition to supporting full pass through of rebates and discounts to plans, we also support ensuring that rebates and discounts flow through to consumers in the form of lower cost sharing, especially when patients are paying coinsurance, and improved access through lower copays and removal of barriers like step therapy and prior authorization.

**Enrollee Access to Cost Sharing Information**

As discussed above, health plan enrollees are subject to higher and higher cost sharing. Even savvy customers who try to determine the cost of their care are simply told that no one – neither the provider’s office or the insurance company – can provide that information. This is especially true for enrollees with a high deductible plan and whose plan includes coinsurance. The beginning part of the plan year—when attempting to meet their deductible—is particularly challenging for people. Frequently, the first time that enrollees learn who much they will owe is when they receive the bill.
For these reasons, we support the proposal to require the provision of good faith estimates of enrollee cost-sharing prior to the provision of a health care service. However, we wish to reiterate that this move will only solve part of the problem. Too many enrollees cannot afford their cost sharing. We encourage the committee to continue to work on the high cost of health care, including high cost sharing.

Title IV: Improving Public Health
Expanding Capacity for Health Outcomes
We support the proposal to provide grants to evaluate, develop, and expand the use of technology for collaborative learning and capacity building. For people living with epilepsy, access to specialty care – including epileptologists – is crucial for developing effective treatment plans. Unfortunately, too many people do not have access to these services, especially people living in rural areas. We support the effort to use technology to increase access to specialty health care services in medically underserved areas and for medically underserved populations.

Public Health Data System Modernization
We support the proposal to expand and modernize public health data systems at the Centers for Disease Control and Prevention (CDC). Such an effort will improve data collection, simplify provider reporting, and improve interoperability. We encourage the committee to consider authorizing appropriations of at least $100 million per year for this important effort, while maintaining funding for other important CDC priorities like $11.5 M for the National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program.