



January 29, 2016

The Honorable Orrin G. Hatch
219 Dirksen Senate Office Bldg.
U.S. Senate Finance Committee
U.S. Senate
Washington, DC 20515

The Honorable Ron Wyden
219 Dirksen Senate Office Bldg.
U.S. Senate Finance Committee
U.S. Senate
Washington, DC 20515

The Honorable Johnny Isakson
219 Dirksen Senate Office Bldg.
U.S. Senate Finance Committee
U.S. Senate
Washington, DC 20515

The Honorable Mark Warner
219 Dirksen Senate Office Bldg.
U.S. Senate Finance Committee
U.S. Senate
Washington, DC 20515

Dear Senators:

Thank you for the opportunity to comment on the bipartisan Chronic Care Working Group Policy Options Document, and applauds your efforts to improve chronic care coordination individuals living with chronic conditions like epilepsy.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of nearly 3 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 people living with epilepsy must have meaningful and timely access to physician-directed care and specialists, to avoid breakthrough seizures and related complications and costs.

Medicare's Six Protected Classes Policy

Of particular importance to the epilepsy community is the preservation of Medicare's six protected classes policy, which was designed to ensure Medicare Part D beneficiaries living with chronic conditions like epilepsy have meaningful and timely access to lifesaving medications necessary for controlling their conditions and maintaining their quality of life. Epilepsy medications are not interchangeable and people living with epilepsy need access to the full range of therapies available so they can find the right medication or combination of medications that most effectively treats their condition.

Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by the physician and patient. As a result, managing these serious, chronic, and life-threatening conditions requires access to the full range of therapies available. To change, limit, or deny access to medications as prescribed by the treating physician can be extremely dangerous and often leads to preventable seizures, increased hospitalizations, and associated complications, including death. These preventable complications result in increased medical costs for Medicare along with lost wages and productivity, not just for the individuals living with epilepsy but also their families and communities.

Patient Engagement When Determining Value

Achieving meaningful input from beneficiaries, particularly individuals living with chronic conditions and/or disabilities, and their families, is a continuous process that requires targeted, proactive strategies beyond regulatory notice and comment. Beneficiaries input is vital to achieving the Center for Medicare & Medicaid Innovation's



(CMMI) goals. The Working Group should consider meaningful engagement strategies like the creation of a Patient Advisory Panel by CMMI that can help ensure new payment models are aligned with care that patients value. The Affordable Care Act calls for evaluation of payment models against “patient-centeredness criteria” yet no such criteria have been formally developed or publicly released for comment by CMMI. Patient should be directly involved in the development of these criteria, which can provide a structured patient-focused framework to guide CMMI’s work.

Developing Quality Measures for Chronic Conditions

The Commission recognizes the need for quality measures that address patient and family engagement, shared decision making, and care coordination. The Working Group should consider a definition for what is a chronic condition that focuses on the impact of a condition on the individual to inform, and this broad definition should in turn inform coordination of care policies and quality measure development and assessment.

We support requiring that the Centers for Medicare and Medicaid Services (CMS) include in its quality measures plan the development of measures that focus on health outcomes that matter patients with chronic disease. This should include quality measures appropriate for the millions of non-elderly Medicare beneficiaries who qualify based on a permanent disability and who have different needs that must be taken into account. This is particularly important for the epilepsy community because a significant number of Medicare beneficiaries living with epilepsy are under the age of 65 and qualify for Medicare due to the severity of their condition.

Additionally, measures that recognize that optimal care may be slowing, rather than improving or maintaining, the rate of decline. Additionally, we support prioritizing measures to which providers are held accountable in a way that truly reflect outcomes that matter to patients and do not place undue administrative burdens on providers.

CMS should engage patients throughout the development and use of quality measures to ensure that they reflect patient values and preferences, including patient input when identifying measure gaps and assessing when measures may need to be updated or replaced. The Working Group should consider the recommendations from the National Quality Forum workgroup on people dually-eligible for Medicare and Medicaid. Additionally, the Working Group should consider the six gaps in existing quality standards directly related to people with disabilities identified by the Consortium for Citizens with Disabilities (CCD).

Transparency at CMMI

We support the Working Group’s consideration of policies to improve transparency at CMMI and agree that modifications are needed to require CMMI to issue notice and comment rulemaking for all mandatory models and at least a 30-day public comment period for all other innovation models. Of particular importance is a required notice and comment period for proposed care models that will have a significant impact on Medicare beneficiaries, such as models that would seek to limit Medicare coverage or access to services. Rulemaking and public comment should include information about how the model is incentivizing high-quality patient-centered care, including any measures that are being used to evaluate the model.

Cost-Sharing Incentives

We support lowering or waiving deductibles to encourage improved access to care and particularly preventive care, as well as exploring whether waiving copayments or coinsurance when there is a proven clinical effectiveness would be viable. Increase cost sharing as an incentive would be less effective especially with the low income, vulnerable population being served by Medicare. Changing the cost-sharing structures would not be sufficient as there is a



general lack of beneficiary awareness and we encourage the Working Group to consider additional outreach and educational initiatives so beneficiaries are aware of their options.

Function and Caps

The Working Group recognizes the importance of function in the Medicare population and should consider broadening its definition of chronic care management to more fully include an individual's functional status as a key measure in chronic care delivery. Coverage of skilled therapy and skilled nursing services supports maintenance of functional status and prevents deterioration of function. A focus on function would also improve access barriers related to caps and the current exceptions process, which often result in denial of rehabilitation services to Medicare beneficiaries who need the services the most. Caps often don't meet the needs of Medicare beneficiaries, particularly those with chronic or multiple conditions and we support eliminating the outpatient therapy caps.

Rehabilitation Services and Devices

Maximizing functional status and independent living for beneficiaries with chronic conditions will save Medicare significant dollars in the long term. The Working Group should consider inclusion of policy proposals that advance access to appropriate rehabilitation services and devices. Despite rehabilitation being key to the ability of beneficiaries with chronic conditions to maintain their functional status and independence while managing their comorbid illnesses or conditions, the Policy Options Document makes no reference to rehabilitative services and devices.

The Epilepsy Foundation supports the Working Group's efforts to improve chronic care coordination and looks forward to continuing to work with the Working Group as it explores legislative proposals to achieve improved health outcomes for individuals living with chronic conditions and their families. Please do not hesitate to contact Angela Ostrom, Chief Operating Office & Vice President Public Policy, at 301-918-3766 or aostrom@efa.org with any questions or concerns.

Sincerely,

A handwritten signature in black ink that reads "Philip M. Gattone".

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