



January 27, 2016

The Honorable Orrin Hatch  
Chairman  
Senate Finance Committee  
219 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Ron Wyden  
Ranking Member  
Senate Finance Committee  
219 Dirksen Senate Building  
Washington, DC 20510

The Honorable Johnny Isakson  
Co-Chair  
Chronic Care Working Group  
131 Russell Senate Office Building  
Washington, DC 20510

The Honorable Mark Warner  
Co-Chair  
Chronic Care Working Group  
475 Russell Senate Office Building  
Washington, DC 20510

Re: Bipartisan Chronic Care Working Group Policy Options Document  
Submitted electronically at [chronic\\_care@finance.senate.gov](mailto:chronic_care@finance.senate.gov)

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson, and Senator Warner:

The Cystic Fibrosis Foundation supports the development of treatments for cystic fibrosis, coordinates a network of cystic fibrosis (CF) care centers, and provides a wide range of educational, patient services, and other resources to CF patients and their families. Through these activities, we help CF patients live longer and healthier lives with their disease.

Our goal is the cure of CF. Until there is a cure for CF, we seek optimal management of CF as a chronic disease. Because CF is a multi-organ disease, managing it requires access to multi-disciplinary care across a patient's lifetime and the effective coordination of all of the elements of high-quality CF care.

We commend the Bipartisan Chronic Care Working Group for its efforts to develop a wide range of policy options for improving the quality of care for those with chronic diseases. In past years, we were significantly focused on delivery and payment of care for children with CF. However, as a result of treatment advances and significant improvements in the system of care for individuals with CF, the median age of survival is now about 40 years. Moreover, for the first time, more than half of all people with CF are age 18 and older. CF is no longer primarily a pediatric disease.

**National Office**

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Today, people with CF are living into their 30s, 40s, and beyond. As a result, Medicare reforms now have direct implications for individuals with CF. For those who become Medicare beneficiaries, it is critical that they have ongoing access to the system of care through which they have received state-of-the-art care and effective coordination of multi-disciplinary care. We are writing to share the important advances in management of CF as a chronic disease and to urge you to consider some of the principles of CF care in your ongoing work.

### ***The Definition of a Chronic Condition***

In the policy options document, there is emphasis on individuals with multiple chronic conditions. We understand the aim of the Working Group to properly target special chronic care services and management of care to those with pressing chronic care needs. Although those with more than one chronic condition may have special needs, others with a single chronic condition may have comparable needs for care coordination, special services, and care planning.

For example, CF is a rare genetic disease that affects multiple organs. Typically diagnosed in infancy or childhood, CF is a progressive disease that requires aggressive management from the time of diagnosis and across a lifetime of care. Those diagnosed with CF require multi-disciplinary care from the time of diagnosis, and they would benefit from care coordination services that are key elements of most of the policy options.

### ***Access to Specialized Care Teams***

With financial and other support from the CF Foundation, a network of CF care centers has been established. The medical professionals and health care institutions that are part of this network provide CF care according to best practice and are engaged in ongoing quality improvement efforts. Because CF is a disease affecting multiple organs, the care teams include pulmonologists, infectious disease specialists, nutritionists, mental health professionals, and others. In addition, CF patients are partners in their care and contribute to quality improvement and clinical development efforts through trial participation and data sharing.

This system of care has been a major factor in the improvements in life expectancy for CF patients. Among the keys to the success of the care network are the training and continuing medical education of the professionals in the network, communication among the professionals in the network, and ongoing quality improvement efforts.

As payment and delivery systems evolve and are reformed, it is critical that care networks that are working well for their patient population are accommodated or retained. A new payment and delivery system that is intended to enhance care coordination and boost quality of care should not put at risk those systems that are already providing these benefits. We appreciate the difficulty of aligning payment systems with quality delivery systems. However, in certain cases the goal must be sustaining existing successful care delivery systems.

### ***Expanding Supplemental Benefits to Meet the Needs of Chronically Ill Medicare Advantage Enrollees***

We strongly support the proposal to encourage Medicare Advantage plans to offer a wider array of supplemental – both medical and non-medical social services – than they currently offer. CF patients benefit from -- in fact, they require -- access to many services that are typically not covered by third-party payers because they are non-medical services.

We are persuaded that the benefits of access to certain non-medical services would extend beyond the benefits enjoyed by CF patients. The health care system, including payers, would benefit from a more comprehensive approach to benefits provided to those with chronic diseases. For example, CF patients need nutritional services that are not typically reimbursed by payers. These are considered non-medical services, but providing CF patients access to such services results in better outcomes. This is just one example of a non-medical service that can improve the health care outcomes for those with CF. We believe the same is true for many others with chronic diseases.

We also note that CF patients are actively engaged – in fact, on a day-to-day basis -- in the management of their disease. We encourage the use of technology to enhance their engagement in their care. Again, we anticipate that use of technology would benefit others with chronic disease.

### ***Improving Care Management Services for Individuals with Multiple Chronic Conditions***

The Working Group asks for comment on a high-severity chronic care management code that could be billed for services that physicians perform outside face-to-face encounters. Input is sought regarding which chronic care patients should be eligible for this service.

Providing reimbursement for physician services to coordinate care, including those performed outside the face-to-face encounter, is an important step toward improvement of chronic care services. Although we do agree that services provided outside the patient-physician encounter are currently unrecognized and that this situation should be rectified, we note the need for enhanced reimbursement for high-severity chronic care management in the face-to-face setting, as well.

We note that the options paper includes a proposal for an initial planning and care coordination visit for those who are newly diagnosed with Alzheimer's or other life-threatening illnesses. Such a visit is probably advisable for certain populations, but it would not address the ongoing need for coordination of care for patients with CF and certain other chronic diseases. CF patients require complex, multi-disciplinary care that addresses symptoms affecting multiple organs. The services and time that must be committed to care coordination are significant and should be appropriately reimbursed.

We support the recommendations of the working group to establish a care coordination code that reimburses for physician services provided outside a face-to-face visit and to establish an initial planning and coordination service for those diagnosed with Alzheimer's and certain other life-threatening

illnesses. However, we think that these two services should be complemented by a high-severity care management service for those whose chronic diseases require complex and ongoing care coordination and refinements in care plan. Such visits are a strategy for improving CF care, sustaining the engagement of CF patients in their care, and avoiding unnecessary emergency department visits and hospitalizations. Such a service is in the best interest of those with CF and the health care system.

We appreciate the opportunity to comment on the policy options for chronic care improvement that have been proposed. We look forward to ongoing communication about these chronic care management efforts.

Sincerely,

A handwritten signature in black ink that reads "Preston W. Campbell, III". The signature is written in a cursive, flowing style.

Preston W. Campbell, III, MD  
President and Chief Executive Officer