

June 28, 2016

The Honorable Orin Hatch
Chairman
Committee on Finance
United States Senate
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member
Committee on Finance
United States Senate
Washington, DC 20510

Dear Chairman Hatch and Ranking Member Wyden:

The undersigned patient and disease advocacy organizations representing a diverse array of Medicare beneficiaries are writing to thank you for convening today's hearing on the proposed Medicare Part B Drug Payment Demonstration. As organizations that represent Medicare beneficiaries living with a broad range of chronic and disabling health conditions, we have a number of concerns with the proposed Demonstration put forward by the Centers for Medicare and Medicaid Innovation (CMMI) and appreciate that the Finance Committee is willing to engage in oversight regarding the design and potential impact of program on beneficiaries.

Many of our organizations have submitted comments to CMMI on this proposed Demonstration expressing concerns on a range of issues, including:

- While this has been deemed a "demonstration" by CMMI, participation will be mandatory for many physicians and their patients and will affect 75% of the Medicare population, making it much larger than a typical demonstration project.
- The payment methodology outlined in Phase 1 of the Demonstration has significant potential to limit access to the full range of available treatments under Part B to treat serious illnesses and conditions such as cancer, arthritis, multiple sclerosis, primary immune deficiency, macular degeneration and schizophrenia.
- Patients often have to try several different treatment options before finding one that works for them. Under the Demonstration, patients could be forced to switch from the most appropriate treatment or discontinue treatment because of transportation hurdles.
- CMMI's Phase 2 proposals to engage value assessments of treatments based on the "average" patient fail to capture the complexity of medical co-morbidities and the diverse complex needs of individual patients. Many of the patients who will be affected have rare and/or chronic diseases and are not the average patient.
- There was a lack of stakeholder input from the beginning of this process, and many of the problems with the Demonstration could have been mitigated had patient groups been involved on the front end.
- There is concern that this Demonstration could have an impact beyond Part B, and ultimately affect patient access to Part D drugs.

While there are several consumer groups that have come out in support of this Demonstration, it is important to note that consumers and patients are two very different constituencies. Patients are the

ones utilizing the health care system on a regular, on-going basis, and should be protected and considered most thoroughly throughout this process.

We are grateful for the Committee's willingness to carefully examine the proposed CMMI Demonstration with a particular focus on how it will impact access to treatment for Medicare beneficiaries that live every day with life threatening and chronic illnesses. We urge you to demand answers from CMMI and would encourage your efforts to block full implementation of this Demonstration until these questions are answered.

Thank you for your leadership in ensuring that the concerns of patients are addressed. Please contact Sandie Preiss, Vice President of Advocacy and Access at the Arthritis Foundation with any questions at spreiss@arthritis.org, 202 887 2910.

Sincerely,

AIDS Institute
Alliance for the Adoption of Innovations in Medicine (Aimed Alliance)
Alliance for Patient Access
American Autoimmune Related Diseases Association
Arthritis Foundation
Asthma and Allergy Foundation of America
Caregiver Action Network
COPD Foundation
Epilepsy Foundation
GBS|CIDP Foundation International
Global Healthy Living Foundation
Health HIV
Hemophilia Federation of America
Hepatitis Foundation International
Immune Deficiency Foundation
International Foundation for Autoimmune Arthritis
Lupus and Allied Diseases Association
Lupus Foundation of America
MLD Foundation
National Alliance on Mental Illness
National Council for Behavioral Health
National Psoriasis Foundation
NeedyMeds
Partnership to Improve Patient Care
Prevent Blindness
Pulmonary Hypertension Association
RetireSafe
Scleroderma Foundation
Sjogren's Syndrome Foundation
U.S. Hereditary Angioedema Association
Veterans Health Council
Vietnam Veterans of America

