

End the Two-Year Wait for Medicare

May 22, 2009

Honorable Max Baucus
Chairman
Committee on Finance
U.S. Senate
Washington, DC 20510

Honorable Charles E. Grassley
Ranking Member
Committee on Finance
U.S. Senate
Washington, DC 20510

Dear Senator Baucus and Senator Grassley,

The Coalition to End the Two-Year Wait for Medicare is grateful for the Senate Finance Committee's efforts to expand access to affordable health care coverage and in particular for outlining concrete steps to eliminate the delay in coverage for a group of Americans most in need of health care — the estimated 1.8 million people with severe disabilities who are waiting to become eligible for Medicare coverage. The policy options presented in *Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans* represent a recognition by the Committee that the waiting period for coverage is unjustifiable and a commitment to move towards its elimination. The organizations of health care advocates and providers represented by our Coalition thank you for taking this stance.

The Coalition to End the Two-Year Wait for Medicare is dedicated to the complete elimination of the waiting period. The two-year wait for Medicare puts effective treatment and care for people with severe disabilities at risk. Many forgo medical treatment and/ stop taking medications, compromising their already fragile health and resulting ultimately in conditions that are often more costly to treat when Medicare coverage finally begins. According to a recent report from The Commonwealth Fund, there is a marked decline in the health status of individuals after entering the waiting period; While about 12 percent of individuals in the second year prior to SSDI entry report being in poor health, that percentage more than doubles among those in the year prior to SSDI entry and rises substantially for those in the first year after disability, and 13 percent of people die during the 24 months before Medicare coverage begins.

The coalition favors Approach 3, which would reduce the waiting period in six month increments, with complete elimination after one-and-a-half years. Approach 2, which would phase-out the waiting period by 2015, is the next best option. We urge the Finance Committee to set its sights on complete elimination of the waiting period and to use the duration of the phase-out period as the chief mechanism to accommodate budgetary pressures.

The coalition has concerns about Approach 4, which would maintain the waiting period for people with access to private insurance that meets or exceeds an actuarial standard. An actuarial standard does not guarantee that coverage is affordable. An actuarial standard does not ensure that out-of-pocket costs for health care are limited, particularly to the majority of people with disabilities with low incomes. We are concerned that private coverage that meets an actuarial standard could still have benefit caps or restrictions on services vital to people with disabilities, such as prosthetics or durable medical equipment. Additionally, while the actuarial standard is being defined in regulation and a mechanism is established to screen out people with access to private coverage, there will be an inevitable delay in beginning the phase-out of the waiting period. The coalition has concerns about the impact of such a delay on the remainder of the people with disabilities without any access to insurance.

The Coalition believes that Approach 1, which would reduce the waiting period to 12 months, represents the least beneficial option. While we recognize the fiscal pressures facing the committee, we believe adopting this option squanders the opportunity to eliminate the waiting period represented by health reform. There is no policy justification for maintaining a waiting period.

No one with a disability severe enough to qualify for SSDI should be without health coverage. We thank you for including these approaches in the coverage options, and look forward to working with you to ensure passage of legislation that provides affordable health care coverage for all Americans, including people with disabilities.

ACCSES
Advocacy for Patients with Chronic Illness, Inc.
AIDS Action Baltimore, Inc.
AIDS Treatment Activists Coalition
AIDS Treatment Data Network
AIDS Treatment News
Alzheimer's Association
American Autoimmune Related Diseases
Association
American Cancer Society Cancer Action
Network (ACS CAN)
American Council of the Blind (ACB)
American Federation of State, County, and
Municipal Employees (AFSCME)
American Foundation for the Blind (AFB)
American Medical Rehabilitation Providers
Association (AMRPA)
American Network of Community Options and
Resources (ANCOR)
American Psychological Association
Amyloidosis Support Groups

Arthritis Foundation
Association for Ambulatory Behavioral
Healthcare
Association for Frontotemporal Dementias
Association of Community Cancer Centers
Association of Programs for Rural Independent
Living (APRIL)
Autism Society of America
Bazelon Center for Mental Health Law
Breast Cancer Network of Strength
Brooklyn Center for Independence of the
Disabled
Center for Disability Rights, Inc.
Center for Independence of the Disabled in
New York (CIDNY)
Center for Medicare Advocacy
Children's Tumor Foundation
Coalition for Pulmonary Fibrosis
Community Health Charities of America
Easter Seals
Eastern Maine AIDS Network (EMAN)
Ehlers Danlos National Foundation
Families USA
Geriatric Mental Health Alliance of New York
HIV/AIDS Services for African Americans in
Alaska
HIVictorious, Inc.
Independence Care System
International Pemphigus and Pemphigoid
Foundation
Kennedy's Disease Association
Medicare Rights Center
Men's Health Network
Mental Health America
Missouri Disability Coalition for Healthcare
Reform
Myasthenia Gravis Foundation of America
(MGFA)
National Academy of Elder Law Attorneys
(NAELA)
National Alliance on Mental Illness (NAMI)
National Committee to Preserve Social Security
and Medicare (NCPSSM)
National Council on Independent Living (NCIL)
National Down Syndrome Congress
National Family Caregivers Association
National Health Law Program (NHeLP)
National Multiple Sclerosis Society
National Organization of Rare Disorders
(NORD)

National Organization of Social Security
Claimants' Representatives (NOSSCR)
National Patient Advocate Foundation
New Mexico AIDS Services
New York Citizens' Committee on Aging
NYFHAC
Options for Independence, Inc.
Paralyzed Veterans of America
Positive East Tennesseans
Project Inform
Pulmonary Hypertension Association
Regional Center for Independent Living
The Resource Center for Accessible Living, Inc.
Rose F. Kennedy University Center for
Excellence in Developmental
Disabilities
Shwachman Diamond Syndrome Foundation
Southern Tier Independence Center
Special Needs Alliance
Syncope Trust and Reflex Anoxic Seizures
(STARS)
The AIDS Institute
The Arc of the United States
United Cerebral Palsy
United Spinal Association