July 12, 2013

Carolyn W. Colvin
Acting Commissioner of Social Security
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

Dear Acting Commissioner Colvin:

The undersigned organizations ask your continued support for the Social Security Administration's Compassionate Allowances Program, a program that has been uniformly successful in enabling SSA to provide benefits with minimum delays to the most obviously disabled individuals in our society.

The entire patient community enthusiastically and without reservation encourages continued support for this program which, as of May 2013, had benefited 301,132 people since it was initiated in 2008.

The Compassionate Allowances Program enables SSA to expedite the processing of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) disability claims for applicants whose medical conditions are so severe that their conditions obviously meet Social Security's definition of disability. As you know, it is not a separate program from SSA's two disability programs, SSDI and SSI.

Before the Compassionate Allowances Program was created, it often took several years to process benefits applications for people with medical conditions that were so severe that they clearly met the definition of disability. During the waiting time, many patients passed away, and others were put into difficult financial straits as they faced their diseases. The Compassionate Allowances Program has significantly reduced the time between the receipt of the application and the provision of needed benefits.

Thus far, 200 medical conditions have been identified that qualify for the Compassionate Allowances Program. These conditions represent about 6% of disability claimants. The conditions that qualify for fast-track processing were selected based on information received at seven public outreach hearings, comments received from the Social Security and Disability Determination Services communities, counsel of medical and scientific experts, and SSA's research with the National Institutes of Health.

We in the patient community recognize the enormous challenges facing our nation, and the need to focus attention on those programs that truly are essential. The Compassionate Allowances Program is one such program that also saves the federal government resources. In a time when legitimate questions are raised about some federal programs, there is unanimous recognition that the Compassionate Allowances Program is needed, is beneficial, is efficiently run, and is worthy of enthusiastic and unqualified support.

All of us are patients and many of us have faced or someday will face diseases that cause disability. It is comforting to know that benefits available under SSDI and SSI for certain carefully selected medical conditions will not be delayed.

Sincerely,

Adenoid Cystic Carcinoma Research Foundation
AKU Society of North America
Alpha-1 Association
Alpha-1 Foundation
Alternating Hemiplegia of Childhood Foundation
American Autoimmune Related Diseases Association
American Behcet's Disease Association
American Brain Tumor Association
American Lung Association
Amyloidosis Support Group
Aplastic Anemia & MDS International Foundation
Association for Frontotemporal Degeneration
Association for Glycogen Storage Disease
Barth Syndrome Foundation
Benign Essential Blepharospasm Research Foundation
Cardio-Facio-Cutaneous International
CADASIL Association
Coalition for Pulmonary Fibrosis
Congenital Heart Information Network
Council for Bile Acid Deficiency Diseases
Cutaneous Lymphoma Foundation
Cystinosis Research Network
Dystonia Medical Research Foundation
EDS Today – Ehlers-Danlos Syndrome (EDS) Advocates
Fabry Support & Information Group
Fibromuscular Dysplasia Society of America
Frank Sasinowski, Member of the NORD Board of Directors
GBS/CIDP Foundation International
Guthy-Jackson Charitable Foundation
Hemophilia Federation of America
Histiocytosis Association
Huntington’s Disease Society of America
Hypoparathyroidism Association
Immune Deficiency Foundation

Incontinentia Pigmenti International Foundation
International Myeloma Foundation
Little Miss Hannah Foundation
Lymphedema Advocacy Group
Marlene Haffner, MD, MPH, Member of the NORD Medical & Scientific Advisory Committee
Mastocytosis Society
M-CM Network
MitoAction
National Ataxia Foundation
National Brain Tumor Society
National Marfan Foundation
National MPS Society
National Niemann-Pick Disease Foundation, Inc.
Neurofibromatosis Network
Pachyonychia Congenital Project
Pancreatic Cancer Action Network
Parent Project Muscular Dystrophy
PSC Partners Seeking a Cure
Phelan-McDermid Syndrome Foundation
National Organization for Rare Disorders
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
Scleroderma Research Foundation|
Soft Bones, Inc.
Trimethylaminuria Foundation
Tuberous Sclerosis Alliance
Vestibular Disorders Association

For additional information, contact Diane Edquist Dorman, Vice President for Public Policy with the National Organization for Rare Disorders, ddorman@rarediseases.org, (202) 588-5700 ext. 102.