



NORD Press Release

Social Security Announces 38 Additional Compassionate Allowance Conditions

Social Security Commissioner Michael Astrue announced this morning the expansion of Social Security's "Compassionate Allowances" program, which provides expedited review of disability applications from people with severely disabling conditions. The announcement was made in a press release. Originally, a press conference had been scheduled for today, and NORD President and CEO Peter L. Saltonstall was to have joined Mr. Astrue at the podium. However, the press conference was canceled because of the recent snowstorms in Washington DC.

The Compassionate Allowances program, launched under Mr. Astrue's leadership in 2008, began with a list of 50 diseases, including 25 rare diseases and 25 cancers. This is the first expansion of the disease list.

The Social Security Administration (SSA) selected the 38 diseases from ones recommended during public hearings and a process of information-gathering. NORD's Medical Advisory Committee provided input to SSA during this process, as did medical experts from the National Institutes of Health and other organizations.

Mr. Astrue has noted that he and his staff intend to continue to identify additional conditions that should be added to the Compassionate Allowances list. The following is the press release sent out by SSA just minutes ago:

Social Security Adds 38 New Compassionate Allowance Conditions

Expansion Will Speed Benefits to Thousands of Americans with Disabilities

Michael J. Astrue, Commissioner of Social Security, today announced that the agency is adding 38 more conditions to its list of Compassionate Allowances. This is the first expansion since the original list of 50 conditions - 25 rare diseases and 25 cancers - was announced in October 2008. The new conditions range from adult brain disorders to rare diseases that primarily affect children. The complete list of the new Compassionate Allowance conditions is attached.

“The addition of these new conditions expands the scope of Compassionate Allowances to a broader subgroup of conditions like early-onset Alzheimer’s disease,” Commissioner Astrue

said. "The expansion we are announcing today means tens of thousands of Americans with devastating disabilities will now get approved for benefits in a matter of days rather than months and years."

Compassionate Allowances are a way of quickly identifying diseases and other medical conditions that clearly qualify for Social Security and Supplemental Security Income disability benefits. It allows the agency to electronically target and make speedy decisions for the most obviously disabled individuals. In developing the expanded list of conditions, Social Security held public hearings and worked closely with the National Institutes of Health, the Alzheimer's Association, the National Organization for Rare Disorders, and other groups.

"The diagnosis of Alzheimer's indicates significant cognitive impairment that interferes with daily living activities, including the ability to work," said Harry Johns, President and CEO of the Alzheimer's Association. "Now, individuals who are dealing with the enormous challenges of Alzheimer's won't also have to endure the financial and emotional toll of a long disability decision process."

"This truly innovative program will provide invaluable assistance and support to patients and families coping with severely disabling rare diseases," said Peter L. Saltonstall, President and CEO of the National Organization for Rare Disorders (NORD). "On behalf of those patients and families, I want to thank Commissioner Astrue and his enthusiastic team for creating and now expanding a program that will have a direct impact on the quality of life of thousands of individuals."

"The initiative not only assists those whose applications are quickly processed, but also assists those whose applications need more time and attention from SSA adjudicators," said Marty Ford, Co-Chair, Social Security Task Force, Consortium for Citizens with Disabilities. "We are pleased to see today's expansion and look forward to working with Commissioner Astrue on further expansion of this decision-making tool and other ways to expedite determinations and decisions for disability claims."

"We will continue to hold hearings and look for other diseases and conditions that can be added to our list of Compassionate Allowances," Commissioner Astrue said. "There can be no higher priority than getting disability benefits quickly to those Americans with these severe and life-threatening conditions."

Social Security will begin electronically targeting these 38 new conditions March 1.

For more information about the agency's Compassionate Allowances initiative, go to www.socialsecurity.gov/compassionateallowances.

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New Compassionate Allowance Conditions

- Alstrom Syndrome
- Amegakaryocytic Thrombocytopenia
- Ataxia Spinocerebellar
- Ataxia Telangiectasia
- Batten Disease
- Bilateral Retinoblastoma
- Cri du Chat Syndrome
- Degos Disease
- Early-Onset Alzheimer's Disease
- Edwards Syndrome
- Fibrodysplasia Ossificans Progressiva
- Fukuyama Congenital Muscular Dystrophy
- Glutaric Acidemia Type II
- Hemophagocytic Lymphohistiocytosis (HLH), Familial Type
- Hurler Syndrome, Type IH
- Hunter Syndrome, Type II
- Idiopathic Pulmonary Fibrosis
- Junctional Epidermolysis Bullosa, Lethal Type
- Late Infantile Neuronal Ceroid Lipofuscinoses
- Leigh's Disease
- Maple Syrup Urine Disease
- Merosin Deficient Congenital Muscular Dystrophy
- Mixed Dementia
- Mucosal Malignant Melanoma
- Neonatal Adrenoleukodystrophy
- Neuronal Ceroid Lipofuscinoses, Infantile Type
- Niemann-Pick Type C
- Patau Syndrome
- Primary Progressive Aphasia
- Progressive Multifocal Leukoencephalopathy
- Sanfilippo Syndrome
- Subacute Sclerosis Panencephalitis
- Tay Sachs Disease

- Thanatophoric Dysplasia, Type 1
- Ullrich Congenital Muscular Dystrophy
- Walker Warburg Syndrome
- Wolman Disease
- Zellweger Syndrome