

**Statement  
of  
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**Social Security Administration**

**Public Hearing**

**Compassionate Allowances for Rare Diseases**

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Good afternoon, my name is Steve Gibson, and I am Vice President of Government Relations and Public Affairs for The ALS Association. I appreciate the opportunity to speak with you this morning on behalf of The ALS Association and people living with Lou Gehrig's disease across the country. We are pleased to partner with the Social Security Administration as it examines Compassionate Allowances and other ways to improve and expedite the disability determination process. I hope that our testimony today will provide you with a better understanding of the nature of ALS and how people with rare diseases like ALS interact with the Social Security Administration. I also will provide examples of some of the problems people with ALS have experienced in filing for Social Security benefits and look forward to sharing suggested solutions to those problems.

### **ABOUT THE ALS ASSOCIATION**

The ALS Association is the only national not-for-profit health association dedicated solely to the fight against ALS, or Lou Gehrig's disease. Through our nationwide network of Chapters, Centers and clinics, The Association serves as a vital resource for ALS patients and their families and also advocates for increased funding for ALS research and other health care policies that respond to the needs of people with ALS and their families.

The ALS Association also is among the world's largest private sources of funding for ALS-specific scientific research, having awarded nearly \$40 million in the past decade to fund research seeking to identify the cause, means of prevention and cure for ALS.

## **ABOUT ALS**

Amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease, is a progressive, neurodegenerative disease that erodes a person's ability to control muscle movement. ALS is designated as an orphan disease, with an estimated 13,000 to 30,000 people living with the disease in the United States today. Approximately 5,000 people are diagnosed each year and about the same number die from the disease annually. The disease also is difficult to diagnose and is often misdiagnosed, for there is no single test to determine whether someone has ALS. Rather, a diagnosis is made after eliminating other possible diagnoses.

Because the disease is relatively rare, many people are not familiar with its symptoms, its progression, or its paralyzing and fatal outcomes. They do not know that once a person develops ALS, their condition will never improve and will only get worse. As the disease advances, people progressively lose the ability to control their muscles: to walk, move their arms and hands, talk and even blink an eyelid. Yet their minds are largely unaffected. They are isolated and awake, alive with the knowledge that they are trapped inside a body they no longer can control. Ultimately, the disease robs a person of the most basic human function – the ability to breathe, as people with ALS generally die from respiratory failure because they no longer can control the muscles needed to breathe. It is a horrific disease.

The average lifespan for a person with ALS is two to five years from the time of diagnosis. However, the disease progresses differently in different people and about 50% die within 18 months of diagnosis. There is no known cause, cure or means of prevention for the disease.

While advances in medicine and technology have helped to prolong life and improve quality of life by treating the symptoms of ALS, there currently is no effective treatment available that reverses, stops, or slows the progression of the disease. One drug has been approved by the FDA to treat ALS, but that drug, Rilutek, which was approved in 1995, only prolongs life by a few months and only in some patients.

The disease also can strike anyone at any time, regardless of age, race, gender or nationality. However, while we are seeing ALS more frequently diagnosed in younger Americans – those in their twenties and thirties - the average age of onset is between 40 and 60 years-old. In other words, the disease impacts people in the prime of their life. Those raising and supporting families; active members of our communities. Your friends and neighbors; colleagues and coworkers.

### **SOCIAL SECURITY BENEFITS**

The benefits available through the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs, including access to Medicare, are invaluable resources to people with ALS and ones on which they rely to enable them to continue to live productive lives and obtain needed health care while they also fight their

disease. These benefits are particularly important to people with ALS. The disease generally strikes people in mid-life while they are productive members of the workforce, supporting themselves and their families. And unlike some other diseases, ALS progresses rapidly and generally is not chronic, providing a family little opportunity to prepare for the sudden loss of income, not to mention the hundreds of thousands of dollars it costs to care for a person with ALS and to support their needs. Those costs include the cost of medical equipment like power wheelchairs, bipap machines and ventilators, speech generating devices, physician services, prescription drugs, in home support services, handicap accessible transportation, home modifications, and many others. They include the loss of a spouse's income, for they often serve as the primary caregiver, and the additional costs that are required to meet a family's day-to-day needs – needs which were once met by the person now fighting the disease.

It is not unusual for a person with ALS to go from working full time to being confined full time to a power wheelchair in less than a year. This rapid change, combined with the significant financial and medical costs of the disease, makes it especially important for people with ALS to access Social Security benefits, and subsequently Medicare, in a timely manner.

Until relatively recently, people with ALS have experienced problems accessing Social Security benefits. For example, some people with ALS have been determined not to be disabled simply because they were able to walk into a Social Security office. Even though the disease may have impacted their speech and the ability to use their arms, some

were denied disability benefits or forced to appeal decisions. Even though the disease impacted their ability to walk, to eat and to participate in substantial gainful activity, they experienced denials and delays. The system, quite simply, did not effectively recognize the progressive, debilitating nature of the disease. It did not recognize that just a few months after an application was denied or delayed, many of these same people would be confined to wheelchairs; some nearly completely paralyzed and others no longer even alive. The system did not know what ALS was and how rapidly it can rob an active, vibrant person of the ability to function - how the disease can disable a person and take from him or her those things which most of us take for granted.

These difficulties were occurring despite the fact that ALS was included in the Listings of Impairments, under the neurological body system section. Part of the problem was that some within SSA, field offices and state agencies had never heard of ALS, or amyotrophic lateral sclerosis. While they may have heard of Lou Gehrig, they knew little or nothing of his disease or that it was included on the Listing of Impairments. However part of the problem also concerned the manner in which ALS was listed. In addition to an ALS diagnosis, a person also needed to demonstrate that they experienced significant “bulbar” signs, such as difficulty swallowing, and speaking, or significant interference with their ability to use their arms or legs. If the disease had not progressed to these points at the time of application, they were denied benefits, regardless of a diagnosis of ALS.

We are pleased to report that in recent years, much has changed thanks to actions taken by the Social Security Administration. In August, 2003, the Social Security Administration published new rules that: 1) changed the listing for ALS, making it easier to qualify for SSDI; and 2) added ALS to the list of conditions, “specific impairment categories,” that automatically qualify for presumptive disability payments under SSI.

Under the new listing for ALS, only medical evidence demonstrating that a person has ALS is needed to meet the listing and to be found disabled. They no longer had to also demonstrate significant bulbar signs or difficulty using their arms and legs. In short, the regulations recognized that those things would happen and that SSA ultimately would find a person with ALS to be disabled.

Importantly, the new rules also enabled people with ALS to qualify for presumptive disability payments simply on the allegation of ALS. This too appears to have expedited access to much needed benefits.

The SSA’s decision to recognize the progressive and disabling nature of ALS also helped people with ALS to take advantage of legislation passed by Congress in 2000 and implemented in 2001 that waives the 24-month Medicare waiting period for people disabled with ALS. Prior to the waiver, many people disabled with ALS died while waiting for Medicare benefits. The system had failed them.

## **CURRENT EXPERIENCES**

As I have mentioned, ALS is a rare disease that unquestionably qualifies for disability under SSA's Listing of Impairments. It should stand to reason, then, that people with ALS should not experience difficulties filing for Social Security benefits. I am pleased to report to you that the anecdotal evidence – the experiences we hear from our Chapters and individual patients – shows that the system appears to be working for most people with ALS. In the majority of cases that come to our attention, people with ALS are able to access benefits in a timely fashion. Claims generally are allowed quickly, although in some cases it can take longer than expected and require a patient to take additional steps to demonstrate disability.

While it is difficult to tell for certain, there are a few factors that we believe contribute to problems and delays. However, the most common problem appears to be a lack of familiarity with the disease or understanding of its progressive nature on the part of field offices and state agencies. Unfortunately, that is one of the challenges with a rare disease like ALS – people may have heard of Lou Gehrig, but they do not know about ALS. In addition, it appears that in many of these cases, field offices and state agencies are not aware that ALS is included on the Listing of Impairments and that a diagnosis, supported by medical evidence, is all that is needed to qualify. Other problems include lost or missing paperwork or difficulties in rural areas where there may be less experience with ALS. Additional problems that are encountered by people with ALS are not related to disability, but to work requirements, like the 20-40 rule, and the five-month waiting

period. We recognize that these latter issues fall outside of the scope of this discussion today and also involve statutory changes.

Ultimately, most of these cases are resolved favorably and, since 2003, we and our Chapters have encountered fewer instances of difficulties. It should be noted that there are several reasons why we believe problems appear to be occurring less frequently and why cases are being resolved favorably. First, since 2003, field offices and state agencies seem to have an increased awareness of the rules that apply to ALS. The rules are no longer new. Second, some of our Chapters as well as the National Association have developed relationships with local offices and SSA staff and conducted other outreach to help educate them about ALS and its inclusion in the Listings. These relationships have helped to expedite claims. Third, we have provided information and guidance to patients applying for disability. For example, we will instruct them to specifically reference the Listings when they apply, contact specific individuals in the local office, cite the regulatory language as well as the SSA Program Operations Manual and the statutory language that included the Medicare waiver for ALS. We educate them about TERI cases (terminal illness) cases and instruct them to request that their case be designated as a TERI case.

In addition to being included in the Listings, the claims of people with ALS also are eligible for expedited processing as TERI cases and individuals are eligible for presumptive disability payments under SSI. Unfortunately, we do not have conclusive evidence that these processes are either working well for people with ALS, or not

working well. We have heard from some Chapters that people qualifying for presumptive disability payments do not receive them – not necessarily because the payments are being denied, but because patients or SSA staff simply may not know that people with ALS automatically qualify for such payments. Again, I want to reiterate that this information is anecdotal in nature. However, SSA should have more definitive information that shows whether people with ALS who qualify for SSI also receive presumptive disability payments.

### **SUGGESTIONS**

The anecdotal experiences of people with ALS appear to demonstrate that the current processes that SSA has established appear to be working for many people with ALS. Yet, we believe improvements can be made.

*Educating and Training Adjudicators:* We believe that it is critical that SSA educate adjudicators about rare diseases like ALS, describing the conditions, their progressive nature and the evidence that is needed to establish disability. Equally important is reinforcing the rules that apply to specific conditions like ALS and training adjudicators to ensure proper implementation of not only of new SSA policies, but also existing policies. For example, in addition to being included on the Listing of Impairments, ALS cases also qualify as TERI cases and also are eligible for presumptive disability payments. It does not appear that adjudicators are consistently aware of these facts and, in some cases today, applicants are the ones educating adjudicators about new and existing policies.

*Community Outreach:* We encourage you to continue to work with us to reach out to the rare disease and disability community and to enlist our assistance in serving these constituencies. Indeed, we welcome opportunities to educate local offices about ALS and to provide information to them that would make their jobs easier, reduce problems to expedite claims.

*Educating the Rare Disease Community:* While SSA has available a variety of publications to inform individuals of disability benefits, their rights and applying for disability, we are not aware of publications or information that is more targeted to those with rare diseases like ALS or those who unquestionable qualify under SSA's Listings. We believe that making such materials available to individuals and organizations could help to further improve the current system and enable them to more easily navigate what can be a complicated and confusing process.

*Technology:* We applaud SSA's initiatives to utilize technology to improve the speed of the disability determinations process and reduce and prevent backlogs. The Quick Disability Determinations (QDD) process is an excellent example of this in which SSA uses computer screening tools to rapidly identify cases that are likely to qualify. We encourage SSA to continue to examine innovative ways like this to apply technology in all facets of the application and review process.

*Streamlining Applications:* Finally, we believe that for those individuals with conditions that unquestionably qualify under SSA's Listings, you consider streamlining the application process that is required to apply for disability or to support a claim. Some of the current requirements, such as indicating the number of steps one can take, are not relevant to people diagnosed with ALS. In fact, they may deter people from applying for benefits or pursuing a claim if they erroneously believe they will not qualify for benefits. We believe SSA should consider processes that permit people with ALS and others who will unquestionably qualify under SSA's Listings to avoid submitting information that may be required for most cases, but is not relevant to their application. For example, applicants could simply be directed to skip certain sections if they have specific conditions like ALS.

Thank you for providing me with the opportunity to speak with you this morning. The ALS Association applauds your efforts to improve the disability determinations process for people with ALS and other rare diseases and disabling conditions – people who often are among those most in need of Social Security benefits. The ALS Association looks forward to working with you and partnering together to advance this important initiative. I am happy to answer any questions you may have.