

equal the prior listing, we evaluate your case further to determine whether you are currently disabled. We may find that you are currently disabled, depending on the full circumstances of your case. See §§ 404.1594(c)(3)(i) and 416.994(b)(2)(iv)(A). If you are a child who is eligible for SSI payments, we follow a similar rule when we decide whether you have experienced medical improvement in your condition(s). See § 416.994a(b)(2).

What Is ALS?

ALS, sometimes called Lou Gehrig's disease, is a progressive, invariably fatal neurological disease that attacks the nerve cells (motor neurons) responsible for controlling voluntary muscles.

ALS most commonly strikes people between 40 and 60 years of age. The diagnosis of ALS is based on history, clinical findings, and electrophysiological and neuroimaging studies. It is also arrived at by ruling out the existence of other neurological disorders that may have similar effects, such as neuropathy.

Eventually, all muscles under voluntary control are affected and individuals with ALS ultimately lose the ability to move their arms and legs, and the capacity to effectively swallow, speak, and breathe. Most people with ALS die from respiratory failure, usually within 3 to 5 years from the onset of symptoms. There is currently no cure for ALS.

What Did the Prior Listing for ALS Require?

The prior listing for ALS, listing 11.10, required that you have ALS with either:

- "Significant bulbar signs" (listing 11.10A) or
- "Disorganization of motor function as described in 11.04B" (listing 11.10B).

"Significant bulbar signs" include difficulty in the ability to chew, swallow, and speak. Listing 11.04B requires "[s]ignificant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements, or gait and station"; in other words, inability to use both of your upper extremities effectively or to walk effectively.

Why Are We Revising the Listing for ALS?

We are revising listing 11.10 because we have determined that it is not necessary to include the requirements in paragraphs A and B of prior listing 11.10. We expect that these final rules will simplify and expedite our

adjudication of claims filed by individuals with ALS.

We receive very few applications based on ALS, and we approve almost all of them at the first level of our decisionmaking process. For example, in calendar year 2002 we received a total of only 1,384 claims based on ALS under titles II and XVI, and the State agencies that review disability claims for us allowed 1,324, or almost 96 percent of them, at the initial level of our administrative review process. The vast majority of the people who appealed their initial determinations denying their claims were also found disabled. In 2002, the State agencies found disabled about 80 percent of the people with claims based on ALS who asked for a reconsideration of their initial determinations. There were similar approval rates for every year since 1999.

There has also been significant Congressional action to help people with ALS qualify for benefits and services as quickly as possible. For example, in 2000, Congress amended the Act to provide that people who are disabled with ALS do not have to wait until they have received benefit payments under title II for 24 months before they can qualify for Medicare, as do all other people who are entitled to disability benefits under title II. See section 226(h) of the Act. These rules will help some people who are disabled with ALS to qualify for Medicare sooner.

We have decided that the simplest and fastest way to process claims of individuals with ALS without sacrificing the quality of our disability determinations and decisions is to revise the listing to provide that anyone who shows that he or she has ALS, established by clinical and laboratory findings, will be found disabled.

Why Are We Adding ALS to § 416.934 of Our Regulations?

The Act and our regulations provide that we may make SSI payments to you for up to 6 months on the basis of presumptive disability before we make a formal determination about whether you are disabled. You must also meet all other eligibility requirements before we may make presumptive disability payments. See section 1631(a)(4) of the Act and § 416.932 of our regulations. (There are no provisions in the Act that would allow us to make presumptive disability payments under title II.) Under § 416.933 of our regulations, we explain that we make these payments if there is a high degree of probability that we will find that you are disabled when we make our formal determination. If

our formal determination is that you are not disabled, the Act provides that you do not have to pay us back.

We may make findings of presumptive disability with or without medical evidence. Section 416.934 of our regulations provides a list of "specific impairment categories" that we use to find presumptive disability without medical evidence. For example, we may make a finding of presumptive disability without medical evidence based on an allegation of Down syndrome. A person meets a listing for Down syndrome (10.06 or 110.06) simply by showing medical evidence establishing that he or she has non-mosaic Down syndrome. Therefore, there is a high degree of probability that we will find people who allege Down syndrome disabled. The new rules for ALS are similar. There is a high degree of probability that we will find people who have ALS disabled when we make our formal determination because everyone who applies for SSI and who has medical evidence showing that they have ALS will be found disabled under revised listing 11.10.

When Will We Start To Use These Final Rules?

We will apply the final rules starting today.

As is our usual practice when we make changes to our regulations, we will apply these final rules to the claims of applicants for benefits that are pending at any stage of our administrative review process, including any claims that are pending administrative review after remand from a Federal court.

What Revisions Are We Making?

We are adding a new section 11.00G to the introductory material in the neurological body system section of our listings. The new section contains three paragraphs. Section 11.00G1 provides some basic information about ALS. Sections 11.00G2 and 11.00G3 provide information about how ALS is diagnosed and the information we need to establish that you meet the requirements of revised listing 11.10. The language of paragraphs 11.00G2 and 11.00G3 is based on language we use in the introductory material to the Down syndrome listings (sections 10.00A and B, and 110.00A and B) and the introductory material to our immune system listings regarding documentation of HIV infection (sections 14.00D and 114.00D).

We are revising listing 11.10 to provide that, if you have a diagnosis of ALS established by the medical evidence described in section 11.00G,