Amyotrophic Lateral Sclerosis Information Page

Synonym(s): Lou Gehrig's Disease

What is Amyotrophic Lateral Sclerosis?

Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's disease, is a rapidly progressive, invariably fatal neurological disease that attacks the nerve cells *(neurons)* responsible for controlling voluntary muscles. In ALS, both the upper motor neurons and the lower motor neurons degenerate or die, ceasing to send messages to muscles. Unable to function, the muscles gradually weaken, waste away, and twitch. Eventually the ability of the brain to start and control voluntary movement is lost. Individuals with ALS lose their strength and the ability to move their arms, legs, and body. When muscles in the diaphragm and chest wall fail, individuals lose the ability to breathe without ventilator support. The disease does not affect a person's ability to see, smell, taste, hear, or recognize touch, and it does not usually impair a person's thinking or other cognitive abilities. However, several recent studies suggest that a small percentage of patients may experience problems with memory or decision-making, and there is growing evidence that some may even develop a form of dementia. The cause of ALS is not known, and scientists do not yet know why ALS strikes some people and not others.

Is there any treatment?

No cure has yet been found for ALS. However, the FDA has approved the first drug treatment for the disease-riluzole. Riluzole is believed to reduce damage to motor neurons and prolongs survival by several months, mainly in those with difficulty swallowing. Other treatments are designed to relieve symptoms and improve the quality of life for people with ALS. Drugs also are available to help individuals with pain, depression, sleep disturbances, and constipation. Individuals with ALS may eventually consider forms of mechanical ventilation (respirators).

What is the prognosis?

Regardless of the part of the body first affected by the disease, muscle weakness and atrophy spread to other parts of the body as the disease progresses. Individuals have increasing problems with moving, swallowing, and speaking or forming words. Eventually people with ALS will not be able to stand or walk, get in or out of bed on their own, or use their hands and *arms.* In later stages of the disease, individuals have difficulty breathing as the muscles of the respiratory system weaken. Although ventilation support can ease problems with breathing and prolong survival, it does not affect the progression of ALS. Most people with ALS die from respiratory failure, usually within 3 to 5 years from the onset of symptoms. However, about 10 percent of those individuals with ALS survive for 10 or more years.

What research is being done?

The National Institute of Neurological Disorders and Stroke (NINOS) conducts research in its laboratories at the National Institutes of Health (NIH) and also supports additional research through grants to major medical institutions across the country. The goals of this research are to find the cause or causes of ALS, understand the mechanisms involved in the progression of the disease, and develop effective treatments.

Results of an NJNOS-sponsored phase 111 randomized, placebo-controlled trial of the drug minocycline to treat ALS were reported in 2007. This study showed that people with ALS who received minocycline had a 25 percent greater rate of decline than those who received the placebo, according to the ALS functional rating scale (ALSFRS-R).

Information provided by the National Institute of Neurological Disorders and Stroke