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ALS Fact Sheet

- ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.
- Every 90 minutes someone is diagnosed with ALS, commonly known as Lou Gehrig's Disease.
- ALS is not contagious.
- It is estimated that ALS is responsible for nearly two deaths per hundred thousand population annually. More people die every year of ALS than of Huntington's disease or multiple sclerosis and it occurs two-thirds as frequently as multiple sclerosis.
- Approximately 5,600 people in the U.S. are diagnosed with ALS each year. The incidence of ALS (two per 100,000 people) is five times higher than Huntington's disease and about equal to multiple sclerosis. It is estimated that as many as 30,000 Americans may have the disease at any given time.
- The average yearly cost of care for a person living with ALS is between \$200,000 and \$250,000.
- ALS occurs throughout the world with no racial, ethnic or socioeconomic boundaries.
- ALS can strike anyone.
- Present treatment of ALS includes one drug, riluzole (Rilutek®) and is aimed at symptomatic relief, prevention of complications and maintenance of maximum optimal function and optimal quality of life. Most of this, in the later stages, requires substantial physical caregiving.
- There can be significant costs for medical care, equipment and home health caregiving later in the disease. It is important to be knowledgeable about your health plan coverage and other programs for which you may be eligible, including SSA, Medicare, Medical and Veteran Affairs benefits.
- Rilutek®, the first treatment to alter the course of ALS, was approved by the FDA in late 1995. This ant glutamate drug was shown scientifically to prolong the life of persons with ALS by at least a few months. More recent studies suggest Rilutek® slows the progress of ALS. Contact your local ALS Association Chapter or the National Office for the Patient Assistance Program resource and more information about access to Rilutek®.

The only ALS-related organization in Massachusetts to provide direct patient services, the ALS Association Massachusetts Chapter provides care today while supporting hope for tomorrow by offering hundreds of ALS patients free services. The ALS Association Massachusetts Chapter is dedicated to provide funding for cutting-edge ALS research, advocacy and public awareness campaigns in the ongoing fight against Lou Gehrig's Disease.