

National Amyotrophic Lateral Sclerosis (ALS) Registry

ALS-Associated and Clinical Factor (ALS Diagnosis)

1. Has any member of your immediate biological family member diagnosed with ALS, Parkinson's, or Alzheimer's disease? (Check all that apply)
 - No
 - Father
 - Brother
 - Don't know
 - Mother
 - Sister
 - Children
2. Compared with the time before you had symptoms of ALS or another motor neuron disease: have you noticed changes in the following? (Check all that apply)
 - No
 - Amount of saliva
 - Handwriting
 - Cutting food and handling utensils
 - Getting dressed and performing self-care activities
 - Walking
 - Breathing and shortness of breath
 - Don't know
 - Speech
 - Swallowing
 - Ways of getting nutrition
 - Feeding tube use
 - Turning in bed and adjusting bed sheet/blanket
 - Climbing stairs
 - Requiring respiratory support (BiPAP®)
3. In what part of the body did you first notice weakness that was diagnosed as ALS? (Check all that apply)
 - Not applicable
 - Arm or hand
 - Leg or foot
 - All over my body
 - Speech and or swallowing muscles
 - Neck, back or abdominal area
 - Breathing muscles
 - Don't know
4. Before you noticed weakness that turned out to be ALS, did you experience any of the following? (Check all that apply)
 - No
 - Scattered muscle twitching
 - Difficulty swallowing
 - Difficulty controlling bowels or bladder
 - Cramps or muscle spasm
 - Difficulty swallowing
 - Problems with speech
 - Don't know
5. Have you ever used/had the following? (Check all that supply)
 - No
 - Breathing equipment (BiPAP®)
 - Communication device
 - Don't know
 - Wheelchair/Electric scooter
 - Tracheostomy
 - Hospice program
6. Since you developed ALS, have you had any of the following? (Check all that apply)
 - No
 - Falls
 - Don't know
 - Pneumonia
 - Blood clot
7. Have you taken the either riluzole (Rilutek®) and/or edaravone (Radicava®)?
 - Yes
 - No
 - Don't know