



The ACT for ALS (S. 1813 / H.R. 3537)

People living with neuromuscular diseases, including ALS, have waited too long for promising treatments.

The ACT for ALS would:

- Accelerate therapeutic development for all rare neuromuscular diseases, including ALS
- Foster greater access to promising experimental ALS therapies
- Facilitate greater coordination of federal government efforts in the fight against all rare neurodegenerative diseases

Accelerate Therapeutic Development

- Creates a brand-new grants program that invests in promising rare neurodegenerative disease research.
- Coordinates private and public research and development efforts to accelerate development of potential lifesaving therapies.
- Commissions a Food and Drug Administration (FDA) action plan on the ways in which the FDA will advance therapeutic development, regulatory science, and policy dissemination to accelerate drug development in rare neurodegenerative diseases.

Greater Access to Promising Experimental Therapies

 Establishes a brand-new grants program to fund expanded access programs and open label extensions for individuals with ALS who are unable to participate in clinical trials.

Greater Coordination of Federal Government Efforts

 Creates an HHS Public Private Partnership (PPP) on Rare Neurodegenerative Diseases to better coordinate federal government efforts in the fight against all rare neurodegenerative diseases.