



With the inauguration of President Joe Biden and the seating of the 117th Congress, we are calling on our national network of ALS advocates to turn their attention to the work of protecting and expanding federal funding for ALS research and fighting for public policies that will accelerate the search for treatments and a cure. The first 100 days of a new presidential administration are critical to advancing public policy, and Congress will soon begin the annual process of funding key government programs. That puts appropriations atop the list of early ALS Association priorities.

Throughout 2020, the ALS community mobilized together to fight for increased funding for ALS research. That work paid off in December when Congress [doubled funding](#) for the Department of Defense ALS Research Program to \$40 million. That was the second time in two years that funding for the program was doubled. NIH funding was increased to nearly \$43 billion, a \$1.2 billion increase. The National ALS Registry was fully funded at \$10 million to continue its important work.

This year, The ALS Association will aggressively pursue new and increased investments in research to find treatments and a cure, slow symptom progression, reduce the number of new cases, and increase the length and quality of life for every American living with ALS.

- **NIH:** Congress should increase funding to at least \$130 million for ALS research at NIH to attract the next generation of neuroscientists, accelerate discovery and development of new treatments and increase the number of ALS clinical trials.
- **DOD ALS Research:** Congress should increase funding to at least \$60 million for the DOD ALSRP to fund clinical trials to pull through promising preclinical research and human studies into ALS drug development.
- **(NEW) FDA:** Congress should provide at least \$50 million for the Orphan Products Grants Program at FDA to fund research to expedite product development, foster innovative trial designs, and enabling natural history studies to better understand the disease progression and pathology.
- **National ALS Registry and Biorepository:** Congress should provide at least \$10 million for this program at CDC to help researchers identify candidates for clinical trials, identify risk factors for ALS and collect biological samples that will aid the search for treatments and a cure.
- **(NEW) National Academy of Sciences:** Congress should provide \$1 million to commission a NAS study to develop a plan and policy recommendations for what can be done by the government and all stakeholders to end ALS.

This appropriations funding will increase the number of ALS clinical trials to find treatments and cures as well as identify risk factors. These investments must also be integrated with increased collaboration across agencies so that discoveries are translated into application. The National Academy of Sciences study will provide a blueprint to achieve these goals.

The successes we saw last year indicate Congress is paying attention to the ALS community and is motivated by its tenacity and unified voice on priority issues and funding opportunities. To build on our momentum, the ALS community must not slow down – we must double down. With your help securing this investment from Congress, we can drastically accelerate the fight against ALS, providing greater hope to every American family affected by ALS.