



## How ALS Association Advocates Boosted Congressional Funding for ALS Research

Last week Congress passed, and the president signed, a continuing resolution that will fund all federal programs at current levels through November 21. Before the continuing resolution expires, Congress must either pass full appropriations bills for the 2020 fiscal year or pass another continuing resolution.

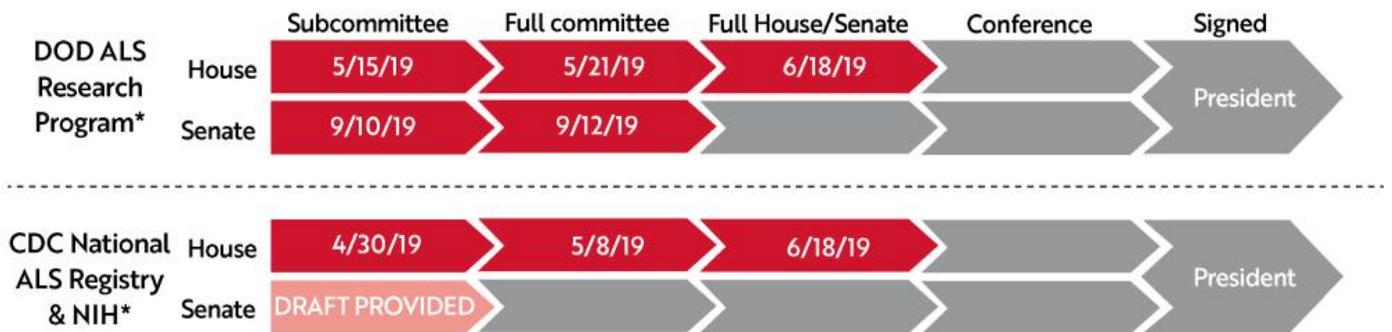
Now that a government shutdown has been averted until just before Thanksgiving, it is worth reflecting on the hard work and success The ALS Association and its advocates have had in securing funding for ALS research and to look ahead to what's next.

[Click here to become an advocate if you have not already!](#)

Federal research funding for ALS is provided by the ALS Research Program (ALSRP) at the Department of Defense, the National ALS Registry at the Centers for Disease Control and Prevention, and the National Institutes of Health. So far, the full House of Representatives and the Senate Appropriations Committee have passed appropriations bills for the 2020 fiscal year that, if passed by both chambers before the continuing resolution expires, would fully fund ALS research at the following levels.

- **ALS Research Program:** \$20 million – a doubling of funds from \$10 million last year – a major achievement in a program area that rarely sees increases of such magnitude.
- **National ALS Registry:** \$10 million – continued funding that continues support for the Registry at current levels.
- **National Institutes of Health (NIH):** \$41.084 billion in the House vs. \$42.084 billion in the Senate  
Here is the current status of fiscal year 2020 appropriations bills for these vital ALS research priorities:

# \$ FY2020 Appropriations



\* H.R. 2740 combines the appropriation bills for Labor/HHS/Education, Defense, State-Foreign Operations, and Energy & Water

The full Senate must now pass a bill to fund the ALSRP, Registry and NIH. Once that happens, the House and Senate will come together in a conference committee to hash out any differences between their respective bills and then send it to the president for signature.

As the largest *philanthropic* funder of ALS research in the world, The ALS Association is laser-focused on increasing federal investments in ALS research, collaborating with the federal researchers to maximize the impact of dollars, and ensuring that the research we fund complements public and private investments across the research continuum.

The ALS Association spearheads annual campaigns to preserve and increase federal funding for ALSRP, the Registry and NIH. In our efforts, we: 1) devise and implement multi-faceted campaigns, 2) directly lobby Congress, 3) mobilize our ALS advocates, 39 chapters and ALS Clinics, and 3) collaborate with other ALS organizations. Here is more about how The ALS Association and advocates like you successfully convinced Congress to preserve and increase funding for ALS research priorities:

# How The ALS Association and Advocates Successfully Convinced Congress to Preserve and Increase Funding for ALS Research Priorities:

Updated our research report on **"ALS and the Military"** which shows that **all military veterans are nearly twice as likely to develop ALS as civilians**, regardless of branch or era of service.



**Enrolled bipartisan congressional champions** to lead a concerted campaign behind the scenes in the House and Senate.

## \$20 MILLION

**Secured the support of 133 representatives and 26 senators** for "Dear Colleague" letters to **increase funding for DOD from \$10 to \$20 million** and fully fund the National ALS Registry at \$10 million. These letters are critically important because they concretely demonstrate Congressional support.

**Supported advocates in meeting with more than 700 members of Congress** at The ALS Association



Chapter Fly-In and National ALS Advocacy Conference. Advocates also conducted many more meetings "back home" in the state or district.

**Submitted 60+ individual office appropriations request forms with every member of Congress** on the House and Senate Appropriations Subcommittees on Defense and Labor-HHS-Education regarding the ALSRP and National ALS Registry.



Activated our ALS advocates through **multiple email campaigns resulting in more than 13,800 letters and more than 3,600 tweets** sent to Congress.



**Mobilized our 39 chapters to target members of Congress** on the House and Senate Appropriations Subcommittees on Defense **to move passive supporters into active champions of the ALSRP increase** during the committee markup process.

**Submitted testimony** to the House and Senate Appropriations Subcommittees on Defense and Labor-HHS-Education regarding the ALSRP and National ALS Registry.



## And much more!

It's because of the hard work of ALS advocates from across the country that we've been able to secure this level of funding. Your advocacy continues to make a big difference for our ALS community. Become an Advocate Today!

