ALS United Statement on Passage of the FY26 Federal Funding Package

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ALS United recognizes the advocates across the ALS community whose sustained engagement helped secure meaningful new investments in ALS research and related programs in the FY2026 federal funding package. By sharing their stories and pressing for urgency, advocates played a critical role in advancing progress for people living with ALS.

Taken together, the FY26 package reflects $45 million in new increases over last year for ALS-focused efforts, including $90 million for ACT for ALS at NIH and a new $30 million investment in ALS research through ARPA-H. The agreement also maintains funding for key programs at the Department of Defense, NIH, and CDC that support the ALS research ecosystem and essential public health infrastructure.

"ALS moves fast, and advocates made it clear that waiting is not an option," said **Jerry Dawson, President and CEO of ALS United**. "Because families and supporters across the country spoke up, we saw real progress this year—especially the $45 million in new funding that will help drive discovery and accelerate the search for better treatments. While these gains are meaningful, they do not yet meet the full need. Advocates will keep pushing until the federal response matches the urgency of ALS."

Key ALS funding outcomes in the FY26 package include:

- $90 million for ACT for ALS at NIH (a $15 million increase over last year)
- $30 million for ARPA-H ALS research (new investment)
- $145 million for NIH ALS research (level funding)
- $40 million for ALS research at the Department of Defense through CDMRP (level funding)
- $10 million for the CDC ALS Registry (level funding)

While ALS United is encouraged by the progress reflected in these final numbers, several priority requests were not fully met. ALS United had advocated for $100 million for ACT for ALS, $80 million for the DoD CDMRP ALS Research Program, $15 million for the CDC ALS Registry, and $180 million for NIH ALS research. The organization will continue working alongside advocates nationwide to build on this year's gains and ensure federal investment reflects the urgency faced by families living with ALS.