

2025 AS Congressional "Asks" At a Glance

Last year, we focused our congressional "asks" on appropriations to advance AS research and drug development at DOD, FDA, and NIH. This year, we are adding legislative asks to support caregivers and health care coverage via Medicaid.

Below is a summary of our three asks this year.

Appropriations Asks (AS-Specific Bucket)

- 1. Fiscal Year (FY)26 Appropriations: Please support AS-specific language in your FY26 appropriations requests. This includes programmatic language to:
 - Continue to include Angelman syndrome as an eligible condition for the Department of Defense (**DOD**) Peer Reviewed Medical Research Program (PRMRP).
 - Families living with Angelman syndrome know that even small improvements in self-care (like dressing or eating) and in navigating their own environment, can be life changing. Encourage the Food and Drug Administration (FDA) to prioritize patient experience data in drug development and review and ensure that treatments delivering meaningful improvements are recognized in the regulatory process.
 - Encourage the National Institutes of Health (NIH) to follow up on the stakeholder convening to support funding for clinical outcome measures, biomarker development, and to ensure timely data sharing across investigators and industry. Oppose cuts to NIH research funding.

Legislation Asks (Care Bucket)

- 2. Credit for Caring: Please cosponsor the Credit for Caring Act to support caregivers and pass the bill into law this Congress.
- 3. Protect Medicaid: Please oppose any proposals that would reduce funding or eligibility for Medicaid.