



2026 AS Congressional “Asks” At a Glance

This year, our congressional “asks” focus on appropriations to advance AS research and drug development at DOD, FDA, and NIH.

Below is a summary of our four asks this year. The remainder of this packet includes all of the background information you will provide in hard copy to your hill staffers (Tab 3) as well as additional background information for further reference only (Tab 4).

Appropriations Asks (AS-Specific Bucket)

1. Fiscal Year (FY)27 Appropriations: Please support AS-specific language in your FY27 appropriations requests. This includes programmatic language to:

- **Department of Defense (DOD):** Continue to include Angelman syndrome as an eligible condition for the Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP).
 - Continued inclusion will sustain critical research funding and support progress toward treatments.
- **Food and Drug Administration (FDA):** Urge the FDA to use the experiences shared by patients and caregivers through the Patient- Focused Drug Development (PFDD) meeting and Voice of the Patient report when reviewing new treatments, and to recognize that **even small gains in communication, mobility, or self-care can be life changing.**
- **National Institute of Neurological Disorders and Stroke (NINDS):** Urge NINDS to fund natural history studies and real-world data collection to better understand the disease and accelerate therapy development.
- **National Center for Advancing Translational Sciences (NCATS):** Urge NCATS to continue to fund gene-targeted and gene editing research in Angelman syndrome that is currently underway.
 - Oppose cuts to NIH research funding that would delay scientific progress and slow the development of urgently needed therapies.