

NFXF FEDERAL RESEARCH FUNDING & LEGISLATIVE POLICY PRIORITIES



Lead



Appropriations:

- Educate and promote awareness of Fragile X- associated conditions and their impact on the community
- Fragile X Caucus- House only
- CDC \$2M/year for FORWARD
- NIH \$104M + in active awards
- DOD Peer Reviewed Medical Research Program (PRMRP) authorized research area
- Proposed cost analysis to enroll adults in FORWARD

Monitor



- Federal Research Funding Opportunities
- Telehealth Policies
- Drug Pricing and Access Policies
- Disability Services and Support Program Policies
 - SSI
 - Education/IDEA
 - Medicaid
 - Vocational Training & Employment Support
- Achieving a Better Life Experience (ABLE) Policies
- Caregiver Support Policies
- Rare Disease Interagency Coordination
- FDA Rare Hub Initiatives
- Rare Pediatric Disease Designation and Priority Review Voucher Programs

Support **Bill numbers from the 118th Congress*



- Accelerating Kids' Access to Care Act [H.R.4758/S.2372](#)
- SSI Savings Penalty Elimination Act [H.R.5408/S.2767](#)
- ENABLE Act [H.R.9614/S.4539](#)
- Creating Hope Reauthorization Act of 2024 [H.R.7384/S.4583](#)
- Home and Community-Based Services (HCBS) Relief Act of 2023 [H.R.6296/S.3118](#)
- Alleviating Barriers for Caregivers Act [H.R. 8018/S. 3109](#)
- Credit for Caring Act of 2024 [H.R.7165/S.3702](#)
- Transformation to Competitive Integrated Employment ACT 2023 (TCIEA) [H.R.1263/S.533](#)
- Disability Employment Incentive Act (DEIA) [S.3076](#)
- Retaining Access and Restoring Exclusivity Act (RARE ACT) [H.R.7383/S.1214](#)
- PROTECT Rare [H.R.6094](#)
- BENEFIT Act of 2023 [H.R.1092/S.526](#)
- KEEP Telehealth Options ACT of 2023 [H.R.1110](#)
- Charlotte Woodward Organ Transplant Discrimination Prevention Act [H.R.2706/S.1183](#)

Strategic Partnerships and Collaborations



- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- Department of Defense (DOD)
- NICHD Strategic Plan 2025 Request for information
- DOD CDMRP/PRMRP Strategic Goals Roundtable
- Everylife Community Congress working groups
 - Public Policy
 - Access & Value
- Friends of NCBDDD
- Defense Health Research Consortium (DHRC)
- Partners that span sectors, other nonprofits, and patient advocacy groups