2026 KIF1A Policy Priorities

About KIF1A.ORG

KIF1A.ORG is a global community dedicated to improving the lives of those affected by KIF1A Associated Neurological Disorder (KAND) and accelerating research to find a cure. KIF1A is a molecular motor protein vital to brain and nervous system function. Mutations in KIF1A cause a severe neurodegenerative disorder with a progressive course. The disease is associated with cognitive impairment, brain atrophy, seizures, limited mobility, spasticity, peripheral neuropathy, vision loss, and can be fatal at an early age. KIF1A Associated Neurological Disorder is a new disease, and research is rapidly underway to discover treatment. Everyday we are closer to understanding KAND and how brain function is disrupted by mutations in the gene. Accelerating this research will lead to rapid development of medicine. Time is as much our enemy as nature. ***We urgently need your support to improve the lives of individuals and families impacted by KAND.***

State 2026 Priorities:

PROTECT MEDICAID: Millions of rare disease patients rely on Medicaid coverage, and without it would be unable to access or afford the care they need. Over half of families with KAND have both private insurance and Medicaid. Moreover, as our children age they will likely become life-long Medicaid beneficiaries. Cutting funding or making it harder for people to access Medicaid benefits, through onerous work requirements, would seriously harm the most vulnerable members of our community.

IMPROVE COVERAGE FOR MAINTENANCE THERAPIES: Individuals living with KAND need consistent access to physical, occupational, and speech therapies to reduce regression and continue to maintain skills. However, health plans often refuse to cover these therapies unless progress can be demonstrated, but for individuals with KAND maintaining skills is progress. Insurance coverage should include the unique needs of individuals living with KAND.

UTILIZATION MANAGEMENT REFORM: Health plans can impose onerous approval requirements, known as prior authorization and step therapy, that can delay or deny access to necessary treatments. These processes should be reasonable, time-orientated, and have exceptions processes in place to allow consumers to avoid these processes when necessary.

Federal 2026 Priorities:

EXPAND ACCESS TO CARE AND TREATMENTS: Federal bills like *Genomic Answers for Children's Health Act (H.R.7118),* which would increase access to genetic sequencing and the *Credit for Caring Act (S.925/H.R.2036)* which would increase caregiver support. *The MINI Act (H.R. 1672),* would clarify that genetically targeted therapies are large molecule drugs under the Inflation Reduction Act, is another important clarification to protect research and investment in rare disease treatments.

Advocacy Best Practices:

- Your story is what legislators and policymakers care about. They want to know (1) what is the problem you experienced; and (2) how legislation or regulation will fix that problem.
- *Advocacy Tip: Write your story down ahead of your meeting with policymakers. This will help you keep on topic and clearly explain how the policymaker can fix your problem.*