June 23, 2026

Michael Caljouw
Massachusetts Insurance Commissioner
Massachusetts Division of Insurance

Dr. Ryan Schwarz
Massachusetts Medicaid Director
Office of Health and Human Services

Dear Commissioner Caljouw and Director Schwarz:

Aimed Alliance is a non-profit health policy organization that seeks to protect and enhance the rights of health care consumers and providers.[1] 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.[2] KIF1A is a molecular motor protein vital to brain function. Mutations in the KIF1A gene cause a severe neurodegenerative disorder with a progressive course. Symptoms of KAND include cognitive impairment, cerebellar atrophy, ataxia, spastic paraplegia, hypotonia, epilepsy, optic nerve atrophy, and peripheral neuropathy.

With our commitments to ensuring access to care in mind, Aimed Alliance and KIF1A.ORG respectfully request that the Massachusetts Medicaid Office and Division of Insurance expand the requirements passed in the Accelerating Kids Timely Access to Care Act to ensure individuals diagnosed and living with rare disorders can access their necessary specialists and care as they age over 21.

I. Rare Disorders & Out-of-State Experts

Nearly 30 million people in the United States live with a rare disorder; an estimated half of these individuals are children.[3] Receiving a rare disease diagnosis is difficult, as rare disorders can present with multiple symptoms, often leading to misdiagnosis until individuals may gain access to the appropriate genetic testing. For example, individuals living with KAND are often misdiagnosed with other forms of epilepsy, cerebral palsy, or ALS.[4] Misdiagnosis not only harms individuals' understanding of disease presentation and progression but can also result in individuals not accessing the most appropriate treatments.

When individuals receive a rare disease diagnosis, it is critical that their care team adequately understands how to treat the condition as the individual ages into adulthood. However, for many rare disorders, this can be challenging as there can be limited research on disease progression, symptom management, and treatment options. For example, the KIF1A mutation was first discovered in 2011, and the first official KAND diagnosis didn't occur until 2017. As a result,

[1] Aimed Alliance, *About Us,* AimedAlliance.Org.
[2] KIF1A, *Mission & Vision,* https://www.kif1a.org/about/mission-vision/
[3] GOA, *Rare Diseases: Although Limited, Available Evidence Suggests Medical and Other Costs Can Be Substantial* (Oct. 2021), https://www.gao.gov/products/gao-22-104235.
[4] KIF1A, *Signs and Symptoms,* https://www.kif1a.org/kand/signs-symptoms/.

research into KIF1A mutations and the impact of the KIF1A protein on the body are still under development and limited to a small group of experts and researchers.

Understanding of disease progression can also be limited for certain smaller or newer rare disease populations. For example, like many rare disorders, KIF1A mutations can only be diagnosed through genomic sequencing and are most accurately diagnosed through whole genome sequencing. Historically, due to a lack of public and private payer coverage, whole genome sequencing has been unavailable to many individuals. However, within the last decade, a growing number of state Medicaid programs have revised their policies to cover some form of genomic sequencing.[5] As a result, many communities for rare disorders are comprised of children or younger populations. Therefore, because the identified population is younger, there is limited understanding of disease progression for individuals as they age among mild, moderate, and severe variations. This is particularly true for the KIF1A/KAND community, which is still learning what adulthood looks like with KIF1A variations.

While limited knowledge on disease progression and lack of treatment options can be challenging for individuals with rare disorders, the growing number of Rare Disease Centers of Excellence offer unique opportunities to access specialized care and gain greater understanding of disease progression and treatment options. Centers of Excellence are not available in every state, and many disease-specific Centers of Excellence are only offered in one state.[6] For example, Dr. Wendy Chung has launched a **KIF1A Next Gen Clinic,** a Center of Excellence care model at Boston Children's Hospital. This center serves as the ***only venue for comprehensive care*** studying KIF1A mutations, disease progression, clinical trials, and treatment options. For families living with KAND, this is the only health care team that can share a detailed, historical understanding of KIF1A mutations and how they may progress or manifest in traditional and non-traditional ways, backed by years of clinical research from this team. This type of knowledge and historical understanding of the condition is not available elsewhere. This situation is similar for many families with rare disorders whose local providers lack the necessary specialty knowledge to properly manage their condition. Therefore, for many families, it is essential to access these specialists without delay. However, due to Medicaid coverage limitations, many individuals living with rare disorders, like KAND, cannot access the out-of-state care or specialists they need.

II. Expand to Include Individuals with Rare Disorders

Recognizing the need for children with complex medical conditions to access experts and out-of-state specialists, Congresswoman Lori Trahan (Mass.) introduced the Accelerating Kids

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[5] GeneDx, *Expanding Access to Genomic Testing: Why Medicaid Coverage Matters,* https://www.genedx.com/blog/medicaid-genetic-testing-coverage#:~:text=Today%2C%2038%20states%20offer%20Medicaid,exome%20and%2For%20genome%20sequencing.

[6] In 2025, the National Organization of Rare Disorders recognized 175 Centers of Excellence across 28 states, https://rarediseases.org/wp-content/uploads/2026/05/NORD-Medicaid-CE-Position-Statement-2026.pdf.

Timely Access to Care Act (AKTAC). AKTAC requires state Medicaid programs to establish a streamlined enrollment process to allow out-of-state providers to enroll in state Medicaid and CHIP.[7] The provisions of AKTAC were passed as Section 6101 of the Consolidated Appropriations Act of 2026.[8] Under the current mandate of Section 6101, states are only required to allow individuals under the age of 21 to access out-of-state providers enrolled through the streamlined process. While Aimed Alliance and KIF1A.ORG support the passage of AKTAC, we respectfully request the Massachusetts expand these requirements to individuals over 21 diagnosed with a rare disease or disorder.

Many children with complex medical needs and rare disorders will remain on Medicaid through adulthood due to disability qualifications, Medicaid Waivers, or similar programs. One analysis of hospital discharge data estimated that nearly 70% of all U.S. adults with rare disorders are Medicaid beneficiaries.[9] As such, this is a population that will likely be Medicaid beneficiaries from childhood through adulthood. Therefore, it is beneficial not only for individual health outcomes but also for Medicaid costs to ensure consistent access to treatment and care as these adults age, thereby avoiding hospitalizations and other costly health events that result from disruptions in care.

For children with complex medical needs and rare disorders, transitioning from childhood care to adult care can be complicated, as many pediatric providers are unable to continue seeing patients after the age of 22. The transition in care can be challenging as providers may feel uncomfortable or unable to take on individuals with rare disorders, resulting in gaps in care for transitioning adults. Moreover, from a broader community perspective, when individuals receive care within Centers of Excellence, health care providers can develop a deeper understanding of disease progression and best practices in treatment, ultimately informing research and treatment options for the entire community. However, when individuals are no longer able to visit Centers of Excellence after a certain age, this data substantially diminishes, leaving families and communities with a weaker understanding of the rare disease, progression, and treatment options.

This challenge is particularly evident for the KIF1A/KAND community. Originally, due to limited access to genomic sequencing, much of the KIF1A/KAND community was younger, under the age of 15. Therefore, families had a very limited understanding of what young adulthood and adulthood would look like for their children. However, with growing access to genomic sequencing and genetic testing, the KIF1A/KAND community is slowly growing to include young adults in their early- to mid-twenties, as well as some older adults in their 40s, 50s, and 60s. Now, with a Center of Excellence model of multi-disciplinary care launching at

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[7] *The Accelerating Kids Access to Care Act Signed Into Law,* https://www.scai.org/media-center/news-and-articles/accelerating-kids-access-care-act-signed-law.
[8] *Id.*
[9] NORD, *Access is Non-Negotiable NORD's Recommendations for Medicaid Work Requirement Implementation,* https://rarediseases.org/wp-content/uploads/2026/05/NORD-Medicaid-CE-Position-Statement-2026.pdf.

Boston Children's Hospital, under Dr. Wendy Chung, the leading global specialist on KIF1A mutations, the KAND community has a unique opportunity to receive specialized care and expand their understanding of disease progression and treatment options. To ensure the availability of these experts is widely accessible, providers like Dr. Chung can now use the simplified enrollment process under AKTAC to ensure care through the KIF1A Next Gen Clinic is covered by state Medicaid programs. However, to ensure individuals are not abruptly disrupted in this care when they turn 22, and allow adults with KAND over the age of 21 to access this specialty care, we respectfully ask your Offices to confirm that providers enrolled in the Medicaid program through the simplified enrollment process are allowed to treat both children in Medicaid and CHIP ***and individuals over the age of 21 with a rare disease or disorder diagnosis*.**

We believe this small expansion to include individuals over the age of 21 with a rare disease or disorder diagnosis will ensure continuity of care for transitioning children and young adults with rare disorders. Practically, without this expansion, children with rare disorders will be disconnected from providers who have treated them for years and understand the complexity of their conditions, resulting in potential negative health consequences and hospitalizations, which are ultimately more costly to the health care system and state Medicaid programs.

III. Conclusion

In conclusion, allowing individuals with rare disorders to access out-of-state specialists already enrolled in the simplified enrollment process under AKTAC can improve health outcomes, disease understanding, and continuity of care for individuals living with rare disorders and their communities. Importantly, the requirements of AKTAC must be implemented within the next three years. Therefore, there is adequate time within this period to expand program eligibility to include individuals diagnosed with rare diseases and disorders.

We greatly appreciate your time and consideration of this request and would appreciate the opportunity to meet with your offices to discuss it in great detail. Please contact avantrees@aimedalliance.org if you have any questions.

Sincerely,

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