

June 18, 2025

The Honorable John Thune
Senate Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Mike Crapo
Chairman, Senate Finance Committee
U.S. Senate
Washington, DC 20510

Dear Leader Thune and Chairman Crapo,

We, the undersigned members of the Institute for Gene Therapies' Patient Advocacy Advisory Council (PAAC), respectfully urge your strong support for the inclusion of the Accelerating Kids' Access to Care Act (S. 752/H.R. 1509) in the upcoming reconciliation package.

Currently, countless children enrolled in Medicaid battling severe and life-threatening conditions often experience unnecessary delays in accessing potentially curative gene therapies. These avoidable delays primarily result from overly complex and burdensome state-by-state Medicaid provider enrollment processes, creating substantial administrative hurdles and significant delays.

Families confronting these circumstances are often forced to endure weeks or even months of uncertainty and frustration while pediatric specialists struggle with repetitive and time-consuming Medicaid credentialing procedures across different states. What's worse – every additional day without treatment risks further disease progression, permanent health complications, or irreversible damage.

In one example, a family from Alaska was forced to navigate considerable logistical obstacles, ultimately requiring intervention from multiple U.S. Senators, to facilitate travel and coordination of care in a Pennsylvania facility. Fortunately, the child ultimately received a lifechanging therapy – but accessing therapies should not be this complicated.

Policymakers can and must simplify and expedite the provider enrollment process. The Accelerating Kids' Access to Care Act effectively addresses these challenges, establishing a five-year reciprocity period for pediatric specialists already vetted through rigorous screening processes in their home states. This approach will significantly reduce

administrative burdens and bureaucratic red tape, facilitating quicker access to essential gene therapies for children.

This legislation enjoys broad bipartisan support, as evidenced by robust co-sponsorship during previous sessions. The Accelerating Kids' Access to Care Act will:

- **Remove Access Barriers**, streamlining burdensome administrative processes for healthcare providers and state Medicaid programs, allowing healthcare professionals to focus on patient care instead of paperwork.
- **Prevent Disease Progression**, minimizing the risk of severe and irreversible health complications by significantly reducing waiting times for specialized pediatric care.
- **Improve Health Outcomes for Children**, ensuring timely and equitable access to lifesaving, FDA-approved gene therapies.

We respectfully request your proactive engagement with Senate leadership to ensure that this critical, bipartisan legislation is included in the upcoming reconciliation package. Your decisive action will make a meaningful and immediate difference in the lives of children who urgently need access to specialized care.

Thank you very much for your attention, leadership, and support on this essential issue.

Sincerely,

[Organization 1]

[Organization 2]

[Organization 3]

(Additional signatories)

[Contact Information]