

April 15, 2024

The Honorable Mike Johnson
Speaker of the House
U.S. House of Representatives
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Chair
House Committee on Energy and Commerce
Commerce
Washington, DC 20515

The Honorable Hakeem Jeffries
House Minority Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
House Committee on Energy and
Washington, DC 20515

RE: Advancing H.R. 4758 Accelerating Kid's Access to Care Act

Dear Speaker Johnson, Minority Leader Jeffries, Chair McMorris Rodgers, and Ranking Member Pallone:

We are writing to urge you to advance the bipartisan Accelerating Kid's Access to Care Act. This Act would improve the ability for children with rare diseases to access timely care and reduce the significant barriers to care many families face as they have to travel out of state for specialized care. The Act has wide bipartisan support with a total of 85 cosponsors, 44 Democrats and 41 Republicans. Despite the strong bipartisan support, this important legislation has not received a vote in Congress.

It is estimated that there are over 7,000 rare diseases, which are defined as diseases affecting 200,000 or fewer individuals. Patients with rare diseases and other complex medical conditions cannot always secure specialized care in their home state. Patients often find that local providers are ill-equipped to treat their rare disease, have technical limitations, or lack the knowledge and experience to treat the rare condition. When this occurs, patients must work with their in-state providers and Medicaid officials to identify out-of-state providers who offer that care. This process is encumbered with regulatory hurdles that often delay and sometimes prohibit patients from receiving critical medical treatments.

While this barrier to care impacts both adults and children with rare diseases, the Accelerating Kid's Access to Care Act, would alleviate these burdens for families with children with rare disease by facilitating coordination across state lines and clarifying the process by which Medicaid and the Children's Health Insurance Program (CHIP) can cover specialized treatments. Medicaid and CHIP serve a vital role in facilitating care for children with rare diseases and other complex medical conditions. By streamlining the screening and enrollment process for pediatric providers to enroll in another state's Medicaid and CHIP programs, the Accelerating Kids Access to Care Act would enable low-income families to more quickly access care and improve quality outcomes for children who require specialized care.

RDDC is a coalition of the nation's leading rare disease and equity advocates, public health experts and industry leaders. We were launched in 2020 to address the extraordinary challenges faced by rare disease patients of color. RDDC and its partners are committed to being a catalyst for progress that guarantees equitable representation of people of color living with a rare disease by seeking to identify and advocate for evidenced-based solutions to alleviate the disproportionate burden of rare diseases on these communities. Importantly, this legislation delivers these benefits while retaining key safeguards to preserve the integrity and efficacy of the Medicaid program.

We strongly urge you to advance this important health equity legislation, and urge you to consider similar legislation for adults who face similar barriers to receiving out-of-state care.

Sincerely,

Jenifer Waldrop
Executive Director
Rare Disease Diversity Coalition