Cosponsor the Accelerating Kids' Access to Care Act (H.R. 1509/S. 752)

Background

For many rare diseases, like hereditary ataxia, there are only a few centers of excellence that have experts in a specific condition in the entire country. This often requires that rare disease patients have to seek care out-of-state.

The Problem

- The majority of rare disease patients are children;
- A significant proportion of patients with rare diseases rely on Medicaid for health insurance;
- According to the National Organization for Rare Disorders (NORD), around 40% of patients travel over 60 miles for care, most of them out-of-state;
- And currently, it is very difficult to get coverage for out-of-state services/providers due to administrative barriers.

Currently, providers must enroll in each state's Medicaid plan separately, which is incredibly time consuming for both providers and states. This administrative barrier also leads to significant delays in care for patients who must go out-of-state for care.

Our Ask:

Cosponsor and help pass the Accelerating Kids' Access to Care Act (H.R. 1509/S. 752)!

The Accelerating Kids' Access to Care Act (H.R. 1509/S. 752)

The Accelerating Kids' Access to Care Act is a bipartisan, bicameral, budget neutral bill that aims to remedy this problem and reduce delays in pediatric care. Specifically, the bill would:

- Create a voluntary, streamlined enrollment process for out-of-state pediatric providers to enroll in state Medicaid programs;
- Make the streamlined process contingent on providers being enrolled in their home state's Medicaid program and maintaining a low risk for Medicaid fraud or abuse;
- And only affect screening and enrollment of pediatric providers. It would not have any effect on authorization or payment for out-of-state care.

Overall, this legislation would alleviate a substantial barrier to care that rare disease patients face. Not only would it reduce delays in care for patients, but it would also lessen administrative burden faced by both pediatric providers and states.

About Us:

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501(c)(3), non-profit organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich's ataxia. Friedreich's Ataxia (FA) is a rare genetic neuromuscular disorder and the most common form of hereditary ataxia.

The National Ataxia Foundation (NAF) is a 501(c)(3) non-profit organization that aims to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia. The ataxias are a group of rare, progressive neurological diseases affecting a person's ability to walk, talk, and use fine motor skills.

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FARA Friedreich's Ataxia Research Alliance