

The Honorable Doris O. Matsui
2311 Rayburn House Office Building
House of Representatives United States
Washington, DC 20515

The Honorable Neal Dunn
466 Canon Office Building United States
House of Representatives
Washington, DC 20515

The Honorable Mike Kelly
1707 Longworth House Office Building
United States House of Representatives
Washington, DC 20515

The Honorable Mike Thompson
268 Cannon House Office Building
United States House of Representatives
Washington, DC 20515

September 4, 2023

RE: PROTECT Rare Act

Dear Representatives Matsui, Dunn, Thompson, and Kelly:

On behalf of the Minnesota Rare Disease Advisory Council, I am writing to express our appreciation for your leadership in advancing the **Providing Realistic Opportunity to Equal and Comparable Treatment (“PROTECT Rare”) Act**. We stand ready to amplify your work to ensure that individuals with very rare conditions have the same intended benefit of health coverage as individuals with more common conditions – access to treatments our physicians know to be the standard of care for our medical conditions.

The bill will build on existing criteria for medically necessary care so that Medicare and Medicaid will be able to consider clinical guidelines and peer-reviewed literature to assess coverage of rare disease treatments. The bill aligns coverage of rare disease treatments to what Congress previously mandated in terms of Medicare coverage for cancer treatments. Importantly, the bill does not provide ‘special treatment’ for rare diseases; rather, it levels the playing field for access to those living with more common conditions.

It will also require private payers to create an expedited review pathway for formulary exception, reconsideration, and/or appeal of any denial of coverage for a drug or biological prescribed for a patient with a rare disorder.

Again, we appreciate your leadership in improving access to the treatments prescribed for rare and ultra-rare patients by their doctors. As an executive branch state agency in Minnesota tasked with improving care for Minnesotans living with rare diseases, we believe this bill would have a positive impact on our rare disease community. Do not hesitate to contact me at erica.barnes@state.mn.us or 651-706-1960 if we can provide further assistance on this important bill.

Respectfully,



Erica Barnes, ccc-SLP



Executive Director
Minnesota Rare Disease Advisory Council