



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

The Honorable Markwayne Mullin
2421 Rayburn 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

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

February 15, 2022

RE: Access to Rare Indications Act (H.R. 6160)

Dear Representatives Matsui, Thompson, Mullin and Kelly:

We are writing to express our appreciation for your leadership in advancing the Access to Rare Indications Act. We stand ready to amplify your work to ensure that individuals with very rare conditions have the intended benefit of health coverage that individuals with more common conditions, and even those with more prevalent orphan diseases, have today – access to health care meeting the standard of care to treat or manage their medical condition(s).

This bill will help level the playing for rare disease patients by allowing Medicare and Medicaid to use sources other than the FDA-approved drug label or compendia to determine whether a treatment prescribed for a rare condition is a medically accepted use. The bill aligns coverage of off-label use of rare disease uses of drugs in Medicare and Medicaid to what Medicare currently mandates in terms of coverage for off-label cancer treatment

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.

This bill ensures that rare and ultra-rare patients are no longer denied access to the care prescribed by their doctors.

We appreciate the opportunity to support this important legislation and look forward to working with you to pass the Access to Rare Indications Act in 2021.

Respectfully,









