Support Access to Treatment for Rare Disease Patients - Cosponsor the Access to Rare Indications Act

Dear Colleagues,

In honor of Rare Disease Week on Capitol Hill (Feb 28-March 2), we invite you to cosponsor H.R. 6160, the Access to Rare Indications Act. This legislation will allow Medicare and Medicaid to use sources including compendia, peer-reviewed literature, and the expertise of rare disease specialists to validate that a prescribed therapy meets the medically accepted criteria used to determine insurance coverage for a rare disease patient. The Access to Rare Indications Act will work to ensure that the 1 in 10 Americans who live with rare diseases have the intended benefit of health coverage and can access evidence-based standards of care for their conditions.

This bill recognizes that over 90% of the 7,000 known rare diseases have no FDA-approved treatment, due to a lack of research in the rare disease space, and challenges in finding enough patients to conduct clinical trials. This leaves many rare and ultra-rare disease patients facing serious and life-threatening illness to rely on off-label use of drugs approved by the FDA for more common conditions. To address this problem, the Access to Rare Indications Act aligns coverage in Medicare and Medicaid for off-label rare disease treatment with Medicare’s existing system used to determine coverage for off-label cancer treatment. Additionally, this bill requires 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.

Please consider supporting this important legislation that will ensure rare and ultra-rare patients are no longer denied access to the prescribed care they need. If you have any questions or would like to become a cosponsor, please contact Christina McCauley with Congresswoman Matsui at Christina.Mccauley@mail.house.gov or Kaitlynn Skoog with Congressman Mullin at Kaitlynn.Skoog@mail.house.gov.

Sincerely,

DORIS MATSUI | Member of Congress

MARKWAYNE MULLIN | Member of Congress

MIKE THOMPSON | Member of Congress

MIKE KELLY | Member of Congress
