



December 20, 2021

The Honorable Eric Swalwell
U.S. House of Representatives
174 Cannon House Office Building
Washington, DC 20515

The Honorable Tom Emmer
U.S. House of Representatives
315 Cannon House Office Building
Washington, DC 20515

The Honorable Scott Peters
U.S. House of Representatives
1201 Longworth Office Building
Washington, DC 20515

Re: Support for the *Precision Medicine Answers for Kids Today Act*

Dear Representative Swalwell, Representative Peters, and Representative Emmer:

On behalf of the Personalized Medicine Coalition (PMC), which represents more than 200 innovators, scientists, patients, providers, and payers to promote the understanding and adoption of personalized medicine concepts, services, and products for the benefit of patients and the health care system, I am writing to express our support for the *Precision Medicine Answers for Kids Today Act*.

The *Precision Medicine for Kids Act* would go a long way toward helping the United States maximize the benefits of genetic testing and genomic sequencing for diagnosing diseases among children whose symptoms are suspected to have genetic causes.

PMC defines personalized medicine as a field in which physicians use diagnostic tests to determine which treatments will work best for each patient or use medical interventions to alter molecular mechanisms that cause disease. By combining data from diagnostic tests with an individual's medical history, circumstances, and values, health care providers can develop targeted treatment and prevention plans with their patients.

Patients with rare undiagnosed diseases, who are often children, currently face a long, invasive, and costly path to diagnosis, known as the diagnostic odyssey. Personalized medicine strategies utilizing genetic testing and genomic sequencing can be valuable tools for discovering changes that contribute to disease development and accelerate care initiation by health care providers. However, certain barriers, including the lack of insurance coverage, can impede access to genetic testing and genomic sequencing for some patients.

We therefore applaud your efforts to begin addressing these barriers with the *Precision Medicine Answers for Kids Today Act* by requiring the Centers for Medicare and Medicaid Services (CMS) to provide guidance to states on how they can

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increase the frequency of coverage for genetic testing and genomic sequencing through the Early and Periodic Screening, Diagnostic and Treatment Benefit Program and by creating a three-year demonstration program at the Department of Health and Human Services for states to cover genetic testing and genomic sequencing and measure how it improves the diagnosis of pediatric health conditions.

Furthermore, by requiring CMS to report on how often genetic testing and genomic sequencing are covered and reimbursed, the bill aims to fill a critical evidence gap standing in the way of removing remaining access barriers. The National Academy of Medicine study detailed in the bill can also make meaningful recommendations about how the federal government can facilitate provider and patient access to personalized medicine in this and other disease areas.

Thank you for your leadership on this bill. We understand that this bill was informed by patients, clinicians, industry, and other stakeholders. As a coalition representing these constituencies, we commend your efforts to incorporate their views. If you have any questions about the content of this letter or if we can be of further assistance as the bill advances through the legislative process, please contact me at cbens@personalizedmedicinecoalition.org or 202-499-0986.

Sincerely,



Cynthia A. Bens
Senior Vice President, Public Policy