PMC
PERSONALIZED
MEDICINE COALITION

October 21, 2019

The Honorable Scott Peters
U.S. House of Representatives
2338 Rayburn House Office Building
Washington, DC 20515

Re: Support for the "Ending the Diagnostic Odyssey Act"

Dear Representative Peters:

I am writing in support of the "Ending the Diagnostic Odyssey Act." The Personalized Medicine Coalition (PMC) comprises more than 200 member institutions from every sector of the health care ecosystem. PMC's mission is to promote the understanding and adoption of personalized medicine concepts, services, and products for the benefit of patients and the health care system. PMC supports legislation that advances the general concept of personalized medicine. This letter is not intended to impact adversely the ability of individual PMC members, alone or in combination, to pursue separate positions on this bill or similar legislation.

We define personalized medicine as a rapidly evolving field that uses diagnostic tools to identify specific biological markers, often genetic, to help determine which medical treatments and procedures will be best for each patient. By combining this information with an individual's medical history and other clinical information, personalized medicine allows doctors and patients to develop targeted prevention and treatment plans.

Scientific discoveries and technological breakthroughs have led to many successes in personalized medicine that are yielding health benefits to patients with chronic, rare, acute and infectious diseases. Whole genome sequencing is a technology that provides large amounts of data on genetic variants that are important for diagnosing some rare diseases. Information on the whole genome can aid a physician in understanding the genetic origin of a disease and selecting treatments that are likely to be effective.

We understand that the "Ending the Diagnostic Odyssey Act" would allow states the option of covering whole genome sequencing services for children on Medicaid who have diseases with suspected genetic causes and funding them with an enhanced Federal match. A state adopting this option would enable vulnerable patients access to services that otherwise would be financially out of reach. Furthermore, this bill's reports on state experience with expanded coverage will help reveal the role whole genome sequencing can play in reducing the time to a rare disease diagnosis, improving a child's clinical outcomes, and reducing Medicaid program expenditures.

Personalized Medicine Coalition
personalizedmedicinecoalition.org
1710 Rhode Island Ave., NW, Suite 700
Washington, DC 20036
P: 202.589.1770
F: 202.589.1778

Thank you for introducing this bill, which calls attention to the promise of a personalized medicine technology in the diagnosis and treatment of rare diseases. As this bill advances, we hope you will work closely with colleagues in Congress who share the larger goal of providing all patients with access to the broadest range of technologies and services for their health conditions. If you have any questions about the content of this letter, please contact me at cbens@personalizedmedicinecoalition.org or 202-589-1769.

Sincerely,

Cynthia A. Bens
Senior Vice President, Public Policy

CC: The Honorable John Shimkus