UNITED MITOCHONDRIAL DISEASE FOUNDATION®

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As the largest the largest patient advocacy group representing those affected by mitochondrial disease, The United Mitochondrial Disease Foundation (UMDF) Fully supports the Advancing Access to Precision Medicine Act, (H.R. 5062), introduced by Reps. Eric Swalwell (CA-15), John Shimkus (IL-15), Scott Peters (CA-52), Erik Paulsen (MN-03), and Juan Vargas (CA-51). If enacted, H.R. 5062 will have a tremendous impact on rare disease diagnosis and treatment, and more specifically, for the more than 160,000 Americans who have confirmed or suspected cases of mitochondrial disease.

The symptoms associated with diseases linked to mitochondrial dysfunction can be extremely diverse and progressive, and the result can be the manifestation of any number of rare diseases that often times can be fatal. There are no known treatments or cures. Mitochondrial disease has also been linked to other, more common diseases, such as Parkinson's or Alzheimer's disease.

The importance of H.R. 5062 for the mitochondrial disease community was highlighted during a recent briefing for members by the Congressional Mitochondrial Disease Caucus. At this briefing, Michio Hirano, MD discussed information from a published report he co-authored for the North American Mitochondrial Disease Consortium (NAMDC). Dr. Hirano is a principal investigator for NAMDC. Both he and NAMDC are based at Columbia University in New York, NY. Dr. Hirano's research revealed that patients who seek a diagnosis for mitochondrial disease may visit up to 20 different physicians during their odyssey. His research also found that in many cases, simple genetic testing could have reduced the time for patients to be diagnosed and decreased the health care costs related to their diagnosis.

The Advancing Access to Precision Medicine Act (H.R. 5062) is important to our patient community because it will direct the Department of Health and Human Services to enter into an agreement with the National Academy of Medicine to develop recommendations on how the federal government may reduce barriers to the utilization of genetic and genomic testing. The bill also would let states apply for an exception to the federal medical assistance percentage rate (FMAP) to provide whole genome sequencing clinical services for certain children on Medicaid who have an unresolved disease that is suspected to have a genetic cause. This is an important first step towards having greater coverage of whole genome sequencing for populations of all ages to improve their access to medical care that directly targets the specific symptoms and nature of their mitochondrial disease.

On behalf of the patients, caregivers, scientists and physicians within the mitochondrial disease community, I urge you to cosponsor the Advancing Access to Precision Medicine Act (H.R. 5062) to improve our community's access to lifesaving medical care. Should you have any questions or wish to cosponsor, please contact Elisabeth Fox (lizzy.fox@mail.house.gov) with Rep. Swalwell or Brian Looser (brian.looser@mail.house.gov) with Rep. Shimkus.

Sincerely,

Brian T. Harman

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