Dear Representative Swalwell,

Thank you for introducing H.R.4393, the Advancing Access to Precision Medicine Act. Our organizations appreciate your strong leadership in helping to end the diagnostic odyssey for rare disease patients. This legislation would ensure that many children and young adults suffering from an undiagnosed condition will have access to DNA sequencing clinical services that are currently out of reach. We are especially pleased that you and your staff worked so closely with the patient and clinician communities in developing this legislation. The undersigned organizations support this bill.

There are more than 7,000 rare disorders that together affect more than 30 million Americans and their families. Approximately 50% of people affected by rare disease are children, and 30% of those children will not live to see their 5th birthday. On average, rare disease patients will see more than 10 specialists and have been misdiagnosed 3 times before receiving an accurate diagnosis. This diagnostic odyssey takes an average of 8 years. This current system is an unacceptable reality.

H.R. 4393 would increase the Federal Medical Assistance Percentage (FMAP) for DNA sequencing clinical services to encourage coverage through state Medicaid plans. The bill would also request the National Academy of Medicine to conduct a study on this expanded coverage to understand how such coverage may improve care, reduce health disparities, and how the federal government may help to reduce barriers to testing.

Diagnostic delays not only costs lives, but often lead to significantly higher treatment costs that would have been unnecessary with a timely diagnosis. We are hopeful that the National Academy of Medicine study included in this legislation will bring this data to light and bring the nation’s diagnostic infrastructure into the 21st century.

Additionally, expanding your legislation to include “DNA sequencing” instead of just “whole genome sequencing” is essential to ensuring patients have the appropriate access to care. During a recent California pilot program to screen babies in the state with an undiagnosed condition through whole genome sequencing, called Project Baby Bear, whole genome sequencing only led to a diagnosis of 43% of the babies tested. The decision of which diagnostic tool is most appropriate should be made by patients and their physicians; not legislated by Congress.

We appreciate the opportunity to work with you to ensure that clinicians and patients have access to the necessary diagnostic tools to ensure a timely and accurate diagnosis. We hope Congress will make the Advancing Access to Precision Medicine Act a priority.
Sincerely,

EveryLife Foundation for Rare Diseases
Bridge the Gap - SYNGAP Education and Research Foundation
The MAGIC Foundation
CureDuchenne
Pompe Alliance
American Society of Gene & Cell Therapy
TEAM for Travis
Little Zebra Fund