Please Co-Sponsor the Advancing Access to Precision Medicine Act (H.R.5062)

Help improve access to affordable lifesaving diagnostic opportunities for kids with rare and undiagnosed diseases.

The bipartisan Advancing Access to Precision Medicine Act (H.R. 5062) was introduced by Representative Eric Swalwell (CA-15) on February 15th, 2018. The bill's original cosponsors are Rep. John Shimkus (IL-15), Rep. Scott Peters (CA-52), Rep. Erik Paulsen (MN-03), and Rep. Juan Vargas (CA-51).

Rare Disease Legislative Advocates (RDLA) works to empower the individual to become an advocate by providing informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to promote rare disease legislation. RDLA's objective is to grow the patient advocacy community and work collectively to ensure that patients have a voice on Capitol Hill.

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Problem: 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. The diagnostic odyssey for rare disease patients takes an average of 8 years.

Solution: The Advancing Access to Precision Medicine Act (H.R.5062) would 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.

The Advancing Access to Precision Medicine Act is supported by the Personalized Medicine Coalition, the EveryLife Foundation for Rare Diseases, Biocom, the Advanced Medical Technology Association, and the American Association for Cancer Research.