



Please Co-Sponsor the RARE Act (H.R. 5115)

Help improve research, surveillance and education for rare diseases.

The bipartisan Rare disease Advancement, Research and Education (RARE) Act (H.R. 5115) was introduced by Representatives Carson (IN-7) and Costello (PA-6) on February 27th, 2018.

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.

Contact: chartman@everylifefoundation.org

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.

Solution: The Rare disease Advancement, Research and Education (RARE) Act (H.R. 5115) of 2018 would provide much-needed investment in rare disease research; direct the Centers for Disease Control and Prevention (CDC) to increase efforts to track and quantify rare diseases; and would require the Agency for Healthcare Research and Quality (AHRQ) to implement rare disease outreach and awareness campaigns for physicians. The bill would also commission additional analysis and recommendations from the National Academy of Sciences on how to accelerate rare disease therapeutic development.

The Rare disease Advancement, Research and Education (RARE) Act is supported by the EveryLife Foundation for Rare Diseases, the National Organization for Rare Disorders and more than 100 other rare disease patient organizations.

RARE DISEASE LEGISLATIVE ADVOCATES 1440 G Street NW, WASHINGTON DC 20005 OFFICE: 202-750-4278 WWW.RAREADVOCATES.ORG @RAREADVOCATES