

Support the Rare disease Advancement, Research, and Education (RARE) Act

Reps. André Carson and Ryan Costello

Almost 7,000 rare diseases affect nearly 30,000,000 Americans, and many lack an effective treatment. There remains much Congress can do to improve rare disease awareness, education, research, surveillance, diagnosis, and treatment, and to address common challenges faced by rare disease patients.

The Rare disease Advancement, Research, and Education (RARE) Act would address some of these commonalities, aiming to improve rare disease treatment, research, and diagnostics. The bill would:

1. Rare Diseases Clinical Research Network/Centers of Excellence

The RARE Act would enhance an existing and successful program of the National Institutes of Health (NIH), the Rare Diseases Clinical Research Network (RDCRN). This unique Network is made up of 21 research ‘centers of excellence’ studying rare diseases in an interdisciplinary way, working with patients and others on clinical studies and other research. The RARE Act would increase and extend the RDCRN’s funding authorization.

2. Surveillance of Rare Diseases

The RARE Act would require the Centers for Disease Control (CDC) to create a National Rare Disease or Condition Surveillance System. Modelled off of similar systems for other conditions, this formalized infrastructure would fill critical gaps in tracking rare disease data, helping researchers to understand commonalities between diseases.

3. Health Professionals’ Awareness of Rare Diseases

The RARE Act would require the Agency for Healthcare Research and Quality (AHRQ) to expand and intensify its work to ensure that health professionals are aware of rare disease diagnoses and treatments.

4. Report

The RARE Act would require the National Academies of Sciences, Engineering, and Medicine to update its 2010 report “Rare Diseases and Orphan Products: Accelerating Research and Development,” to evaluate rare disease efforts and make further recommendations to policymakers.