



Please Join the Rare Disease Congressional Caucus

The bipartisan and bicameral **Rare Disease Congressional Caucus** is led by Representatives G.K. Butterfield (D-NC) and Gus Bilirakis (R-FL) and Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN) to promote awareness of rare disease issues.

Background: There are more than 7,000 rare disorders that together affect more than 30 million Americans and their families. One in 10 Americans has a rare disease. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the U.S. More than 80% of rare diseases are considered ultra-rare, affecting fewer than 6,000 people; some affect fewer than 100 people. Rare diseases include rare cancers, tropical or neglected diseases, genetic diseases and many pediatric diseases including cancers. Many of these diseases are life-threatening and have no treatment options.

The Orphan Drug Act was enacted in 1983 to encourage pharmaceutical companies to develop drugs for diseases that have relatively small patient populations. Despite the success of the Orphan Drug Act, there have been fewer than 700 treatments for less than 550 diseases approved for marketing by the Food and Drug Administration (FDA) in the last 30 years.

The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. Additionally, while a few treatments have become available, patients struggle with insurance companies and government programs to afford these lifesaving treatments.

Solution: The Rare Disease Congressional Caucus helps bring public and Congressional awareness to the unique needs of the rare disease community (including patients, physicians, scientists, and industry), and creates opportunities to address roadblocks to the development of and access to crucial treatments. The Caucus gives a permanent voice to the rare disease community on Capitol Hill. Working together, we can find solutions that turn hope into treatments.

Rare Disease Legislative Advocates (RDIA), a program of the EveryLife Foundation for Rare Diseases, helps coordinate the Rare Disease Congressional Caucus. RDIA 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. RDIA's objective is to grow the patient advocacy community and work collectively to ensure that patients have a voice on Capitol Hill.

Contact: RDIA: vonfelden@curetheprocess.org; **Senator Wicker's office:** Samantha.Elleson@wicker.senate.gov or **Rep. Butterfield's office:** Kyle.L.Parker@mail.house.gov.



Senate Co-Chairs: Senators Roger Wicker (MS) and Amy Klobuchar (MN)

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