



Join the Rare Disease Congressional Caucus

The bipartisan and bicameral **Rare Disease Congressional Caucus** is led by Representatives Doris Matsui (D-CA) 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 over 10,000 rare disorders that together affect more than 30 million Americans and their families. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the United States. Many rare diseases are considered ultra-rare; some affect fewer than 100 people. Rare diseases include genetic diseases, rare cancers, tropical or neglected diseases, and many pediatric diseases. Many of these diseases are life-threatening and have no treatment options.

The Orphan Drug Act was enacted in 1983 to incentivize pharmaceutical companies to develop therapies for diseases that have relatively small patient populations. Despite the success of the Orphan Drug Act, 93-95% of rare diseases still do not have a treatment approved by the Food and Drug Administration.

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 relatively few treatments have been approved, patients struggle with health insurance reimbursement and other coverage barriers that prohibit access to potentially 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 barriers to the development of and access to life-altering treatments. The Caucus gives a permanent voice to the rare disease community on Capitol Hill. Working together we can find solutions that transform hope into therapies and cures.

For more information contact: Vice President of Advocacy, Shannon von Felden at svonfelden@everylifefoundation.org.

To join the Caucus contact: Sen. Klobuchar's office: Ruth.Mcdonald@klobuchar.senate.gov; Sen. Wicker's office: Kendyl.Willox@wicker.senate.gov; or Rep. Matsui's office: Jackie.Weinrich@mail.house.gov.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.

RARE DISEASE LEGISLATIVE ADVOCATES (A PROGRAM OF THE EVERYLIFE FOUNDATION)
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House Co-Chairs: Representatives Doris Matsui (CA-7) and Gus Bilirakis (FL-12)

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