



Please Join the Rare Disease Congressional Caucus

The bipartisan and bicameral Rare Disease Congressional Caucus is led by Representative Leonard Lance (R-NJ), Representative G.K. Butterfield (D-NC), Senator Orrin Hatch (R-UT), and Senator Amy Klobuchar (D-MN) to promote awareness of rare disease issues.

Rare Disease Legislative Advocates (RDLA) helps coordinate the Rare Disease Congressional Caucus. 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: RDLA: sbhatnagar@everylifefoundation.org; Rep. Lance's office: Robert.Butora@mail.house.gov; or Senator Hatch's office: Stuart_Portman@hatch.senate.gov

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. The Orphan Drug Act was enacted in 1983 to encourage pharmaceutical companies to develop drugs for diseases that have relatively small patient populations. 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 diseases affect fewer than 100. 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.

Despite the success of the Orphan Drug Act, there have been fewer than 500 treatments for less than 400 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 to 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 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.

Senate Co-Chairs (established in 2015): Senators Orrin Hatch (UT) and Amy Klobuchar (MN)
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Lance (NJ-7) and G.K.

Representatives Leonard
Butterfield (NC-1)

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Cheri Bustos IL-17
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Tom Marino PA-10
Brian Mast FL-18
Doris Matsui CA-6
Michael McCaul TX-10
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Seth Moulton MA-6
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Bill Pascrell NJ-9
Erik Paulsen MN-3

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