



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: *Vignesh Ganapathy, Associate Director for Advocacy and Government Relations, EveryLife Foundation for Rare Diseases, vganapathy@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.

Upcoming Caucus Briefing:

Thursday, March 2nd, at 12:00pm in Hart Senate Office Building Room 902

Advancing Rare Disease Treatments in the Era of Cures and Health Care Reform

Full event info can be found at www.RareCaucus.org.



Senate Co-Chairs (established in 2015): Senators Orrin Hatch (UT) and Amy Klobuchar (MN)

House Co-Chairs: Representatives Leonard Lance (NJ-7) and G.K. Butterfield (NC-1)

HOUSE

Mark Amodei NV-2
Lou Barletta PA-11
Andy Barr KY-6
Ami Bera CA-7
Eddie Bernice Johnson TX-30
Donald Beyer Jr. VA-8
Gus Bilirakis FL-12
Marsha Blackburn TN-7
Rod Blum IA-1
Suzanne Bonamici OR-1
Mo Brooks AL-5
Julia Brownley CA-26
Vern Buchanan FL-16
Michael Burgess TX-26
Cheri Bustos IL-17
G.K. Butterfield* NC-1
Mike Capuano MA-7
Andre Carson IN-7
John Carter TX-31
David Cicilline RI-1
Barbara Comstock VA-10
Gerald Connolly VA-11
Ryan Costello PA-6
Joseph Crowley NY-14
Rodney Davis IL-13
Suzan DelBene WA-1
Jeff Denham CA-10
Charlie Dent PA-15
Ted Deutch FL-21
John Duncan, Jr. TN-2
Eliot Engel NY-16
Anna Eshoo CA-18
Jeff Fortenberry NE-1
John Garamendi CA-3
Gregg Harper MS-3

Danny Heck WA-10
Jaime Herrera-Beutler WA-3
Jim Himes CT-4
Jared Huffman CA-2
Darrell Issa CA-49
Lynn Jenkins KS-2
Hank Johnson GA-4
David P. Joyce OH-14
Marcy Kaptur OH-9
Joseph Kennedy, III MA-4
Peter King NY-2
Darin LaHood IL-18
Leonard Lance* NJ-7
Dan Lipinski IL-3
Frank LoBiondo NJ-2
Dave Loebsack IA-2
Zoe Lofgren CA-19
Tom MacArthur NJ-3
Carolyn Maloney NY-12
Sean Patrick Maloney NY-18
Kenny Marchant TX-24
Tom Marino PA-10
Doris Matsui CA-6
Michael McCaul TX-10
Jim McGovern MA-2
David McKinley WV-1
Luke Messer IN-6
Tim Murphy PA-18
Richard Neal MA-1
Rick Nolan MN-8
Donald Norcross NJ-1
Frank Pallone NJ-6
Bill Pascrell NJ-9
Erik Paulsen MN-3
Donald Payne, Jr. NJ-10
Scott Peters CA-52

Collin Peterson MN-7
Jared Polis CO-2
Bill Posey FL-8
Mike Quigley IL-5
Ilena Ros-Lehtinen FL-27
Peter Roskam IL-6
David Rouzer NC-7
Jan Schakowsky IL-9
David Scott GA-13
Pete Sessions TX-32
Albio Sires NJ-8
Adam Smith WA-9
Chris Smith NJ-4
Steve Stivers OH-15
Eric Swalwell CA-15
Glenn Thompson PA-5
Pat Tiberi OH-12
Paul Tonko NY-20
Fred Upton MI-6
Juan Vargas CA-51
Tim Walz MN-1
Debbie Wasserman-Schultz FL-23
Bonnie Watson Coleman NJ-12
Joe Wilson SC-2
Robert Wittman VA-1
John Yarmuth KY-3
Kevin Yoder KS-3

SENATE

Tom Cotton AR
Orrin Hatch* UT
Amy Klobuchar* MN
James Risch ID
Chris Van Hollen MD

