



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: jjenkins@everylifefoundation.org; Rep. Lance's office: Robert.Butora@mail.house.gov; or Senator Hatch's office: Lauren_Paulos@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)

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
Lacy Clay MO-1
Barbara Comstock VA-10
Gerald Connolly VA-11
Ryan Costello PA-6
Joseph Crowley NY-14
Rodney Davis IL-13
Peter DeFazio OR-4
John Delaney MD-6
Suzan DelBene WA-1
Jeff Denham CA-10
Charlie Dent PA-15
Ted Deutch FL-21
John Duncan, Jr. TN-2
Mike Doyle PA-14
Eliot Engel NY-16
Anna Eshoo CA-18
Brian Fitzpatrick PA-8
Jeff Fortenberry NE-1
Rodney Frelinghuysen NJ-11
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
Ro Khanna CA-17
Peter King NY-2
Raja Krishnamoorthi IL-8
Darin LaHood IL-18
Leonard Lance* NJ-7
Jim Langevin RI-2
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
Brian Mast FL-18
Doris Matsui CA-6
Michael McCaul TX-10
Tom McClintock CA-4
Jim McGovern MA-2
David McKinley WV-1
Luke Messer IN-6
Seth Moulton MA-6
Tim Murphy PA-18
Richard Neal MA-1
Rick Nolan MN-8
Donald Norcross NJ-1
Steven Palazzo MS-4
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
Chellie Pingree ME-1
Jared Polis CO-2
Bill Posey FL-8
Mike Quigley IL-5
Jamie Raskin MD-8
David Reichert WA-8
Ilena Ros-Lehtinen FL-27
Peter Roskam IL-6
David Rouzer NC-7
Jan Schakowsky IL-9
Brad Schneider IL-10
David Scott GA-13
Pete Sessions TX-32
Kyrsten Sinema AZ-9
Albio Sires NJ-8
Louise Slaughter NY-25
Adam Smith WA-9
Chris Smith NJ-4
Lloyd Smucker PA-16
Chris Stewart UT-2
Steve Stivers OH-15
Eric Swalwell CA-15
Glenn Thompson PA-5
Pat Tiberi OH-12
Paul Tonko NY-20
Niki Tsongas MA-3
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
Lee Zeldin NY-1

SENATE

Christopher Coons DE
Tom Cotton AR
Orrin Hatch* UT
John Hoeven ND
Angus King ME
Amy Klobuchar* MN
James Risch ID
Chris Van Hollen MD