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 known 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 relatively 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 therapies and cures.

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.

Contact: RDLA: vonfelden@curetheprocess.org; Senator Wicker’s office: Sally_Farrington@wicker.senate.gov or Rep. Butterfield’s office: Caitlin.VanSant@house.mail.gov
Senate Co-Chairs: Senators Roger Wicker (MS) and Amy Klobuchar (MN)
House Co-Chairs: Representatives G.K. Butterfield (NC-1) and Gus Bilirakis (FL-12)

HOUSE
Mark Amodei NV-2
Cindy Axne IA-3
Andy Barr KY-6
Joyce Beatty OH-3
Ami Bera CA-7
Eddie Bernice Johnson TX-30
Donald Beyer Jr. VA-8
Gus Bilirakis* FL-12
Sanford Bishop, Jr. GA-2
Lisa Blunt Rochester DE
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
Salud Carbajal CA-24
Andre Carson IN-7
John Carter TX-31
Sean Casten IL-6
Steve Chabot OH-1
Judy Chu CA-27
David Cicilline RI-1
Lacy Clay MO-1
Steve Cohen TN-9
James Comer KY-1
Gerald Connolly VA-11
Jim Cooper TN-5
Jason Crow CO-6
Susan Davis CA-53
Rodney Davis IL-13
Peter DeFazio OR-4
Diana DeGette CO-1
Suzan DelBene WA-1
Ted Deutsch FL-21
Debbie Dingell MI-12
Mike Doyle PA-14
Eliot Engel NY-16
Anna Eshoo CA-18
Abby Finkenauer IA-1
Brian Fitzpatrick PA-8
Jeff Fortenberry NE-1
Ruben Gallego AZ-7
John Garamendi CA-3
Josh Gottheimer NJ-5
Garret Graves LA-6
Danny Heck WA-10
Jaime Herrera-Beutler WA-3
Kevin Herns OK-1
Jim Himes CT-4
Kendra Horn OK-5
Jared Huffman CA-2
Hank Johnson GA-4
David P. Joyce OH-14
Marcy Kaptur OH-9
Joseph Kennedy, III MA-4
Ro Khanna CA-17
Derek Kilmer WA-6
Andy Kim NJ-3
Ron Kind WI-3
Peter King NY-2
Raja Krishnamoorthi IL-8
Darin LaHood IL-18
Jim Langevin RI-2
Susie Lee NV-3
Mike Levin CA-49
Dan Lipinski IL-3
Dave Loebback IA-2
Zoe Lofgren CA-19
Alan Lowenthal CA-47
Blaine Luetkemeyer MO-3
Tom Malinowski NJ-7
Carolyn Maloney NY-12
Sean Patrick Maloney NY-18
Kenny Marchant TX-24
Brian Mast FL-18
Doris Matsui CA-6
Ben McAdams UT-4
Michael McCaul TX-10
Jim McGovern MA-2
David McKinley WV-1
Cathy McMorris Rodgers WA-5
Grace Meng NY-6
Markwayne Mullin OK-2
Seth Moulton MA-6
Richard Neal MA-1
Donald Norcross NJ-1
Eleanor Holmes Norton DC
Steven Palazzo MS-4
Frank Pallone NJ-6
Jimmie Panetta CA-20
Chris Pappas NH-1
Bill Pascrell NJ-9
Donald Payne, Jr. NJ-10
Scott Peters CA-52
Collin Peterson MN-7
Chellie Pingree ME-1
Bill Posey FL-8
David Price NC-04
Mike Quigley IL-5
Jamie Raskin MD-8
Kathleen Rice NY-4
Max Rose NY-11
David Rouzer NC-7
C.A. Dutch Ruppersberger MD-2
John Rutherford FL-4
Jan Schakowsky IL-9
Brad Schneider IL-10
David Scott GA-13
Mikie Sherrill NJ-11
Mike Simpson ID-2
Albio Sires NJ-8
Elissa Slotkin MI-8
Adam Smith WA-9
Chris Smith NJ-4
Jason Smith MO-8
Lloyd Smucker PA-16
Darren Soto FL-9
Jackie Speier CA-14
Chris Stewart UT-2
Steve Stivers OH-15
Eric Swalwell CA-15
Glenn Thompson PA-5
Rashida Tlaib MI-13
Paul Tonko NY-20
Lori Trahan MA-3
Fred Upton MI-6
Juan Vargas CA-51
Nydia Velazquez NY-7
Peter Visclosky IN-1
Ann Wagner MO-2
Greg Walden OR-2
Debbie Wasserman-Schultz FL-23
Bonnie Watson Coleman NJ-12
Joe Wilson SC-2
Robert Wittman VA-1
John Yarmuth KY-3
Lee Zeldin NY-1

SENATE
John Barrasso WY
John Boozman AR
Maria Cantwell WA
Shelley Moore Capito WY
Christopher Coons DE
Tom Cotton AR
John Hoeven ND
Cindy Hyde-Smith MS
James Inhofe OK
John Kennedy LA
Angus King ME
Amy Klobuchar* MN
Edward Markey MA
Jeff Merkley OR
Gary Peters MI
James Risch ID
Kyrsten Sinema AZ
Jeanne Shaheen NH
Tina Smith MN
Debbie Stabenow MI
Chris Van Hollen MD
Roger Wicker* MS

RARE DISEASE LEGISLATIVE ADVOCATES (A PROGRAM OF THE EVERYLIFE FOUNDATION)
1012 14TH STREET NW, SUITE 500, WASHINGTON DC 20005
OFFICE: 202-697-RARE (7273) WWW.RAREADVOCATES.ORG @RAREADVOCATES