Rare Disease Legislation in the Queue

Rebuilding and Expanding the Rare Disease Congressional Caucus

Cristina Might
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• What is a Caucus? •

Forum for **Members of Congress** to...

• **Voice** constituent concerns,
• **Educate** other Members and staff
• **Collaborate** on ideas
• **Facilitate** conversations between relevant stakeholders
• **Build** support for legislation
“The Congressional Rare Disease Caucus is a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases.”
• House Co-Chairs •

• Senate Co-Chairs •

Sen. Orrin Hatch (R-UT)  Sen. Amy Klobuchar (D-MN)
Sen. Orrin Hatch (R-UT)
Briefings

Science Behind Rare Disease Policy

Precision Medicine

The NIH and FDA: Vital Agencies in the Fight Against Rare Diseases

Driving Innovation for Lifesaving Therapies through PDUFA Reauthorization in 2017

Strengthening Medical Innovation in America for Rare Disease Patients

21st Century Cures Initiative: Priorities for the Rare Disease Community

The Rare Disease Ecosystem: Fostering Patient Engagement & Driving Biomedical Innovation
Advancing Rare Disease Treatments in the Era of Cures and Health Care Reform

THURSDAY, MARCH 2ND AT HART SENATE OFFICE BUILDING ROOM 902
Lunch Briefing: 12:00pm – 1:30pm

Moderator: Caroline Kruse, Executive Director, Platelet Disorder Support Association

• Frank Sasinowski, Director, Hyman, Phelps & McNamara PC – “Implementing the 21st Century Cures Act”
• Eric Gascho, Vice President of Government Affairs, National Health Council – “The PDUFA Reauthorization Process in 2017”
• Beth McGinn, Director of Public Affairs and New Media, ARTBA – “The Affordable Care Act Repeal and Replacement”
• Clare Thibodeaux, Ph.D, MBA, Director of Scientific Affairs, Cures Within Reach – “New Models for Rare Disease Drug Development”
• “The Role of Incentives in the Development of Rare Disease Therapies”
• Senate Membership •

*aka The Fab Five*

Arkansas - Tom Cotton

Idaho - James Risch

Louisiana - David Vitter

Minnesota - Amy Klobuchar*

Utah - Orrin Hatch*
• House Membership •

100+

AL • CA • CO • CT • FL • GA
IL • IN • IA • KS • KY • IL • ME
MA • MI • MN • MS • NE • NV
NJ • NY • NC • NE • OH • OR PA
• RI • SC • TN • TX • VA
WA • WV
• House Membership •

MISSING

Alaska, Arizona, Arkansas, Hawaii, Idaho, Louisiana, Maryland, Missouri, Montana, New Hampshire, New Mexico, North Dakota, Oklahoma, South Dakota, Utah, Vermont, Wisconsin, Wyoming
Join the Rare Disease Caucus!