

Tricks of the Trade: Preparing for a Successful Meeting

Congressional Scorecards, Hill Asks and Leave Behinds



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EveryLife Foundation for Rare Diseases



Your Congressional Scorecard

RDLA compiles Legislative Scorecards based upon membership in the Rare Disease Congressional Caucus & action taken on rare disease legislation.

You can find the scorecards in your group folders.

Your state scorecard shows how effective your legislator has been on rare disease issues.

115TH CONGRESS
RARE DISEASE SCORECARD
WASHINGTON

DISTRICT	SENATOR	CAUCUS	S. 1391 BUREAU OF BIOLOGICAL SERVICES ACT OF 2015	S. 1972 PATENT HOLDING IMPACT ASSESSMENT ACT OF 2016	S. 2036 ADVANCING TARGETED THERAPY FOR RARE DISEASE ACT OF 2016	S. 2372 LAMPHIHEDEMA TREATMENT ACT	H.R. 16 THE 21 ST CENTURY CURBS ACT	S. 1461 THE OPEN ACT	S. 1872 THE ADVANCING HOPE ACT OF 2016	115 TH CONGRESS GRADE
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Your Congressional Scorecard

- ▶ Include the Scorecard in your conversation about rare disease issues.
- ▶ If your legislator has a strong score – thank them.
- ▶ If your legislator’s score is poor, ask them what their main concerns were with the legislation.
- ▶ Ask for a commitment for an improved level of support – an easy way to improve their score is to join the Rare Disease Caucus!

115TH CONGRESS
RARE DISEASE SCORECARD
WASHINGTON

DISTRICT	SENATOR	CAUCUS	S. 1394 ENACTING AGREEMENT TO CLINICAL TRIALS ACT OF 2015	S. 1972 PATENT HOLDING IMPACT ASSESSMENT ACT OF 2016	S. 2636 ADVANCING TARGETED THERAPIES FOR RARE DISEASE ACT OF 2016	S. 2572 LAMPHIEMMA TREATMENT ACT	H.R. 14 THE 21ST CENTURY CURES ACT	S. 1461 THE OPEN ACT	S. 1878 THE ADVANCING HOPE ACT OF 2016	115TH CONGRESS GRADE
	Cantwell, Maria	▼	▼	▼	▼	++	+	▼	▼	B
	Murray, Patty	▼	▼	▼	▼	+	+	▼	▼	C
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WWW.RAREADVOCATES.ORG/SCORECARD/

Things to Remember About the Scorecards

- Our goal for is to thank Members of Congress who have truly been champions for rare disease patients.
- Use your scorecard as a tool to help the rare disease community reach out to Members of Congress and educate them on bills that are important to patients.
- A legislator's poor score is a reflection of the work we need to do as advocates to educate legislators on rare disease issues. You'll see the scores on Members that we haven't had meetings with are remarkably lower than the scores of members we have visited. Proof that we have and continue to make a difference on Capitol Hill.

Your Hill Asks & Leave-Behinds



Support Robust Funding for the National Institutes of Health, the Food & Drug Administration, and 21st Century Cures Implementation

Congressional Ask

We request a **\$2 billion increase** in the annual discretionary funding for the 2018 Labor-Health and Human Services-Education Appropriations Act: **\$2.2 billion** in the FY2018 Agriculture Appropriations Act; and, that apply **Innovation fund** dollars for NIH and FDA included in the 21st Cures Act.

Rationale for NIH and FDA

It is estimated that 1 in 10 individuals has a rare disease. There may be 25 million people with rare diseases, but unfortunately, the vast majority (95%) do not yet have a diagnosis. Funding for the National Institutes of Health (NIH) support the biomedical infrastructure across America while driving forward therapies and cures. NIH is the world's leading funder of basic biom breakthroughs in how we understand and treat deadly and debilitating diseases. Research by the NIH generates an estimated \$2.20 in economic activity for every dollar invested in research by the NIH.

The Food and Drug Administration (FDA) plays a critical role by providing innovative medicines and devices that may benefit rare disease patients.

Building on the momentum of 21st Century Cures

The 21st Century Cures Act supports innovation in achieving medical discovery, development and delivery of new treatments and cures through patient voice in the process. The bill created an NIH Innovation Fund to carry out the priorities enacted in legislation. We urge Congress to pass the Innovation Funds for Fiscal Year 2018.

- NIH Innovation Fund: \$496,000,000
- FDA Innovation Fund: \$60,000,000

For more information, please contact: Sara Chang, Director of Policy and Advocacy, schang@researchamerica.org



Please Join the Bipartisan, Bicameral Rare Disease Congressional Caucus

The bipartisan Rare Disease Congressional Caucus is led by Representatives L. Gohmert (D-TX) and G.K. Butterfield (D-NC) in the House and Senators Orrin Hatch (R-UT) and Mark Warner (D-VA) in the Senate. The goal of the Caucus is to promote awareness of rare diseases and ensure that the House has over 100 Members and 6 Members in the Senate.

Rare Disease Legislative Advocates (RDIA) helps coordinate the Rare Disease Congressional Caucus, a collaborative organization designed to support the advocacy of all rare disease patients. RDIA empowers the individual to become an advocate by providing informational meetings, advocacy tools, and special events that support organizations and advocates working on rare disease legislation. RDIA's objective is to grow the patient advocacy community and work to ensure many voices of patients with rare diseases have an opportunity to be heard on Capitol Hill.

Background: There are more than 7,000 rare disorders that together affect more than 25 million people and their families. One in 10 Americans has a rare disease. The Orphan Drug Act encourages pharmaceutical companies to develop drugs for diseases that have small populations. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people. More than 80% of rare diseases are considered ultra-rare, affecting fewer than 6,000 people. Rare diseases include rare cancers, tropical or neglected diseases, many pediatric diseases and cancers. Many of these diseases are life threatening.

Despite the success of the Orphan Drug Act there have been fewer than 450 treatments approved for marketing by the FDA in the last 30 years. The science of how to treat these diseases is often limited; however, treatments may never be developed because of the high cost of development, such as a lack of investment and a challenging regulatory environment while a few treatments have become available for some, patients struggle with government programs to afford these lifesaving treatments.

Solution: The Rare Disease Congressional Caucus helps bring public and Congressional attention to the unique needs of the rare disease community - patients, physicians, scientists, and advocates. Opportunities to address roadblocks in access to and development of crucial treatments give a permanent voice to the rare disease community on Capitol Hill. Working solutions that turn hope into treatments.

To Join the Rare Disease Congressional Caucus: In the House, email Robert Eutora, Robert.Eutora@mail.house.gov, in the Office of Representative Leonard Lance. In the Senate, email Stuart Fortman in the Office of Senator Orrin Hatch, Stuart.Fortman@hatch.senate.gov. Please CC Max G. Bronstein from Rare Diseases Legislative Advocates, mbronstein@everylifefoundation.org.

www.RareAdvocates.org



Principles for Health Coverage Reform

Before the Affordable Care Act (ACA) was enacted in 2010, rare disease patients struggled to access health care coverage due to various discriminatory insurance practices, limited Medicaid eligibility, and debilitating cost-sharing. While imperfect, the Affordable Care Act successfully reformed these practices by forbidding insurers from discriminating against rare disease patients, outlawing annual and lifetime caps, expanding Medicaid, closing the Medicare Part D donut hole, and more.

In order for any ACA replacement plan to not harm rare disease patients, we must:

- ✓ **Protect rare disease patients against discriminatory insurance medical underwriting:**
 - **Guaranteed Issue and Renewal:** Requires insurers to offer insurance to all patients, regardless of health status, during annual open enrollment periods, special enrollment periods, and renewal periods.
 - **Prohibition on Benefit Exclusions:** Ensures discriminatory benefit exclusions or limitations aimed at individuals or groups of individuals with expensive pre-existing conditions are banned.
 - **Community Rating:** Guarantees that patients are not charged higher premiums because of their health status, including if they have a gap in coverage.
- ✓ **Cap out-of-pocket costs at affordable annual or monthly levels:**
 - Under the ACA, the out-of-pocket maximum for 2017 can be no more than \$7,150 for an individual plan and \$14,300 for a family plan before marketplace subsidies. These caps must remain.
- ✓ **Ban annual and lifetime limits on benefits and coverage**
- ✓ **Prohibit any newly-created high-risk pools from including:**
 - Eligibility based upon health status or other discriminatory factors
 - Waiting periods for coverage after enrollment and enrollment caps
 - Benefit caps or medical underwriting
 - Inadequate funds to ensure the viability of the plan
 - Premiums and deductibles higher than the small and large group markets
- ✓ **Allow children to remain on their parents' health plans until age 26**
- ✓ **Oppose plans to weaken Medicaid through financing mechanisms such as block grants or per-capita caps:**
 - Many children with a rare disease and their families are on Medicaid because the high-cost of their disease has resulted in financial hardship.
 - Block granting or instituting per-capita caps can disincentivize states from covering high-cost patients, adding orphan drugs to state formularies, or covering expensive but medically necessary inpatient care, outpatient care, habilitative services, and rehabilitative services.
- ✓ **Maintain coverage for rare disease patients that gained coverage under the ACA Medicaid expansion**
- ✓ **Continue the ongoing closure of the Medicare Part D donut hole**
- ✓ **Keep vital care options, such as the:**
 - **Community First Choice 1915(k) program:** Allows patients in need of skilled-care to stay in the home and out of skilled-nursing facilities under a Medicaid state-option.
 - **Concurrent Care for Children (ACA Section 2302):** Allows children who are enrolled in either Medicaid or CHIP to receive hospice services without forgoing curative treatment for a terminal illness.
- ✓ **Ensure quality health insurance at affordable prices by requiring:**
 - **Essential health benefits:** Requires baseline levels of benefits in small and large group plans, including prescription drugs in each USP class.
 - **Adequate provider networks:** Plans must maintain adequate provider networks for their beneficiaries.
- ✓ **Provide adequate subsidies for low-income Americans**
- ✓ **Adequately and effectively incentivize individuals to purchase insurance while accommodating any valid reason for going uninsured for a period of time**
 - Continuous coverage incentives must accommodate any appropriate and valid reason for going uninsured
- ✓ **Prohibit discrimination against individuals with disabilities (ACA Sec.1557)**

For more information contact Paul Melmeyer, Associate Director of Public Policy, National Organization for Rare Disorders: pmelmeyer@rarediseases.org

Your Hill Asks & Leave-Behinds

- **Be early and keep note of you are meeting.**
 - Is it a Senator? Talk about a bill in the Senate.
 - Is it a staffer? Staffers can often be more helpful since they know the issues off-hand.
- **Coordinate with your team members and be respectful.**
 - You'll only have 2 minutes.
 - Each of you has an important story to tell. Keep yours short and pass the baton.
- **Share your personal story.**
 - Tell them why the issue is important to you.
- **You don't have to be an expert.**
 - If you are asked a question and don't know the answer, write it down & tell them you'll follow up.

Your Hill Asks & Leave-Behinds

- **Be respectful.**
 - Your legislator may not be able to support a specific bill – if they say “no,” ask them to join the caucus.
 - Thank them for agreeing to meet with you.
- **Prioritize**
 - Limit to 1-2 asks, and make sure it’s something the office can actually do.
- **Remember your ask!**
 - Be specific. You want to make sure they remember.
- **Leave-Behinds**
 - Avoid leaving large packets about your disease or organization.
 - One sheet about your bill, your business card, photos... and...

Patient Stories

- **You will be sharing a group packet.**
 - This packet includes your members of Congress' bios and office locations.
- **Stories of patients and constituents who could not make it to DC.**
 - Patient stories are a very valuable leave behind and leave an indelible impact. Make sure to visit the other state offices in your downtime.
 - Look on the left side of your packet for a guide to the offices.
 - The patient stories are on the right side.
- **You are their voice on Capitol Hill.**
 - Remember that you are there on their behalf.
- **The location sheets are not always 100% accurate.**
 - Check office locations when you enter the building.
 - Legislators often change offices.

Need a reminder?

RARE
DISEASE WEEK
ON CAPITOL HILL
FEBRUARY 27 - MARCH 2,

PRESENTED



42



CONGRESSIONAL MEETING TIPS

- ✓ Arrive on time, not more than five minutes early.
- ✓ Share your personal story and explain why the issue is important to you.
- ✓ You don't have to be an expert on legislation. If you are asked a question that you are not sure how to answer, write it down and promise to follow up.
- ✓ Respect a staffer's time by limiting meetings to 20 minutes.
- ✓ Report back to RDLA staff on how the meeting went.
- ✓ Thank each staffer for agreeing to meet with you.
- ✓ Make a specific legislative "ask". You have to give Congress the solutions.
- ✓ Leave behind a one-pager with a summary of each issue as well as your contact information.
- ✓ It's okay to ask for a photo with a Member of Congress. Make it a group shot and do it quickly.
- ✓ Follow up with a thank you note reinforcing your ask.



- **Thank your Member** if they are part of the Caucus.
 - (Hint: you can find out on your Scorecard!)
- If they are not, ask them to join!
- If you are meeting with a Senator:
 - 2015 was the first year with a bicameral Rare Disease Caucus to help elevate Congressional awareness of the rare disease community. We have since grown, but there's still work to do!
 - In order to grow the Caucus in the Senate, we need more Senate Champions to join the Caucus. If they want to join please take note.

And remember...

- **The location sheets are not always 100% accurate.**
- **Check the office locations when you enter the building.**
 - Legislators often change offices.

Questions?

Contact Information:

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Associate Director of Advocacy and Government Relations

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