



Guide to the RDLA Congressional Scorecard

RDLA compiled the scorecard based on membership in the Rare Disease Congressional Caucus and action taken on legislation important to the rare disease community in the 116th Congress. Newly elected Members will not have had an opportunity to cosponsor or vote on bills and therefore will have an N/A listed by their name.

Below are some of the actions and bills included in the RDLA Congressional Scorecard. To view more information on the legislation included in the scorecard, visit <http://www.rareadvocates.org/scorecard>.

Rare Disease Congressional Caucus Membership: This bipartisan, bicameral caucus provides a vital platform for discussing pressing policy issues and gives rare disease patients a voice on Capitol Hill.

Advancing Care for Exceptional Kids Act, H.R.1226/S.317 : The Advancing Care for Exceptional Kids Act (ACE Kids Act) would establish a state Medicaid option to provide for medical assistance with respect to coordinated care provided through a health home (i.e., a designated provider or team of health-care professionals) for children with medically complex conditions.

Ensuring Lasting Smiles Act, H.R.1379/S.560: The Ensuring Lasting Smiles Act would require all private insurance group and individual health care plans to cover diagnosis and treatment services resulting from congenital anomalies and birth defects. Coverage must include services that functionally improve, repair, or restore any body part that is medically necessary for normal bodily functions or appearance, as determined by the treating physician.

Lymphedema Treatment Act H.R. 1948/S.518: The Lymphedema Treatment Act would provide a Medicare benefit category for coverage of the physician-prescribed compression supplies used in the treatment and management of lymphedema.

Newborn Screening Saves Lives Reauthorization Act, H.R.2507/S.2158: The Newborn Screening Saves Lives Reauthorization Act would reauthorize existing federal programs that assist states in improving and expanding programs, support parent and provider education, and ensure laboratory quality and effective surveillance.

Medical Nutrition Equity Act, H.R.2501: The Medical Nutrition Equity Act would provide coverage of medically necessary foods and vitamins for digestive and inherited metabolic disorders, including PKU, under federal health programs and private health insurance.

Creating Hope Reauthorization Act, H.R.4439: The Creating Hope Reauthorization Act would permanently reauthorize the pediatric priority voucher program. This program creates an incentive for companies to develop drugs for pediatric rare diseases.

How to Use the Scorecard:

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

*This scorecard is only a sampling of legislative actions. We recognize that Members in leadership positions refrain from cosponsoring legislation, however their actions can greatly affect passage of rare disease bills. **Poor scores show that the Rare Disease Community still has a lot of work to do to educate Congress on issues that are important to patients.***