



Rare Disease Advocates Storm DC During Rare Disease Week

Over 200 passionate rare disease advocates joined forces in Washington D.C. to attend RDLA's legislative conference and lobby day. During the conference, advocates heard from panels of experts and congressional staff who provided key insights into effective advocacy and updates on the political landscape. Armed with that knowledge, advocates then visited their representatives in the House and Senate, sharing their personal stories and lobbying for legislation on behalf of the rare disease community, visiting over 200 offices! For those who were unable attend, check out our [photos](#), [videos](#), and [program](#) from the conference.



Community Action Alerts:

Stand Up for Health Research Funding

Research!America has issued an [action alert](#) on behalf of health research funding. Annually, members of Congress have the opportunity to influence the appropriations process by submitting their funding priorities to appropriators. Now is the time to ask your representatives in the House and Senate to champion increased funding for medical and health research in the fiscal year 2016.

Sign-on to Protect FDA Funding

The California Healthcare Institute (CHI) is working to protect critical funding for the drug review divisions at FDA, which are under threat of budget cuts that could greatly hamper the drug approval process. Organizations are being asked to endorse legislation, FDA SOS Act HR 1078, to protect these vital funds. [Read the full letter here](#) – organizations that wish to sign-on may email Jenny Carey, carey@chi.org.

Ask Congress to Bring Treatments to Rare Disease Patients

The EveryLife Foundation for Rare Diseases is asking individuals to contact Congress and encourage them to co-sponsor the OPEN ACT HR 971. The OPEN ACT is new legislation that provides a vital incentive for industry to repurpose existing therapies for rare disease indications. This legislation has the potential to double the number of treatment options available to the rare disease community. View [the action alert here and contact Congress today!](#)

Sign-on to Thank Reps. Upton & DeGette for their Leadership

Rare disease groups are circulating an organizational sign-on letter to thank Chairman Upton (R-MI) and Representative DeGette (D-CO) for leading the 21st Century Cures Initiative, and for incorporating the patient voice. To date, over 40 organizations have signed, including: the EveryLife Foundation, Global Genes, Parent Project Muscular Dystrophy, and the Sarcoma Foundation of America. [View the sign-on letter here](#) and email mbronstein@everylifefoundation.org to get signed-on. Please share with your networks so we can send a strong message to Congress!

Help Make the Creating Hope Act Permanent [LINK REPAIRED]

Kids v. Cancer is asking organizations to endorse the ADVANCING HOPE ACT introduced by Representatives G.K. Butterfield, Mike McCaul, Chris Van Hollen, Mike Kelly and Steven Cohen to permanently reauthorize the Creating Hope Act. The Act provides priority review vouchers to companies that invest in pediatric rare disease drug development. [Click here for additional information and to endorse the legislation.](#)

NORD is also circulating a [sign-on letter](#) calling on Congress to make the program permanent. Email Paul Melmeyer if you would like your organization listed on their letter: pmelmeyer@rareidiseases.org. Signing deadline is 12pm (ET) on Wednesday, March 25.

Endorse the “The Kids Initiative” [LINK REPAIRED]

Kids v. Cancer is calling for endorsements for a new legislative proposal to reform existing legislation, the Pediatric Research Equity Act (PREA) and the Best Pharmaceuticals for Children Act (BPCA), in order to give sick kids access to promising unapproved and abandoned adult drugs. [Click here for more information or to endorse.](#)

Sign-on to Preserve GINA & ADA Protections [NEW]

Genetic Alliance is circulating a sign-on opportunity for groups looking to protect the Genetic Nondiscrimination Act and the Americans with Disabilities Act. Recently introduced legislation seeks to exempt employer-based wellness programs from GINA and the ADA. This could allow employers to inquire about employees' private genetic information or medical information unrelated to their ability to do their jobs, and penalize employees who choose to keep that information private. [Click here to view the full letter and to sign-on.](#)

The House & Senate are Accepting Testimony on NIH Funding

The House and Senate subcommittees that handle NIH funding are accepting testimony from organizations who wish to comment on funding for medical research. You may submit written testimony for the record to the [House](#) and/or [Senate](#).

Rare Disease Legislation News

Senator Durbin Introduces the American Innovation Act & American Cures Act

In response to marked declines in federal funding for science and medical research, Senator Durbin (D-IL) has introduced legislation to close the innovation deficit. The [American Innovation Act](#) would boost funding for vital research agencies that support research. [The American Cures Act](#), in particular, would boost and guarantee funding for NIH, CDC, and programs that support medical research for veterans.

FASEB Releases NIH State Fact Sheets

FASEB (The Federation for American Societies of Experimental Biology) has released NIH fact sheets that detail the impact of medical research investment in every state. These sheets are incredibly useful for advocates as they make the case to Congress for boosting investment in NIH funding. [Check out the full set and find your state!](#)

Letter to Ensure Access to Rare Disease Treatments Sent to Congress

Led by the National MPS Society, 135 signing organizations across the rare disease spectrum worked together to deliver a letter to the Energy & Commerce Committee to request common-sense Medicaid reforms on behalf of the rare disease community. This letter will be crucial input as the Committee continues to work on the broader 21st Century Cures Initiative. [Click here to view the final letter.](#)

Rare Disease Community News & Events:

March's RDLA Meeting

Wednesday, March 25 12:00-1:00 pm EST. RDLA convenes once a month to discuss legislation and developments that affect the rare disease community. The tentative agenda will cover legislation relating to FDA and NIH funding, clinical trials, pediatric treatment access, 21st Century Cures, and Medicaid reform for children. [Click here to register](#) or if you wish to suggest an agenda item please email arussell@everylifefoundation.org.

Webinar: FDA's Patient-Focused Drug Development: The view from the other side of the table

Tuesday, April 7, 1-2pm (ET). Since the Patient-Focused Drug Development (PFDD) initiative was launched in 2012, the Food and Drug Administration (FDA) has held or scheduled 14 disease-specific meetings to better understand patients' experience with symptoms, impacts on daily living, and available therapies. With more meetings on the docket for 2015, and growing interest among patient groups in applying the PFDD model to developing their own data, FasterCures examines the experience of organizations engaged in this process. [Register here.](#)

Seeking Feedback from RDLA's Legislative Conference [LINK REPAIRED]

Did you attend RDLA's Rare Disease Week this year? If so, RDLA is seeking your feedback on our Legislative Conference! We need your comments, insight, and advice so we can make the Conference even better in 2016. Please take a few moments to [complete the survey](#).