



21st Century Cures Update & Recap from RDLA Meeting

Last week we were joined by Carly McWilliams from the E&C committee who provided an update on the 21st Century Cures legislation. E&C has been energized by the non-partisan nature of the issue and the outpouring of support from all stakeholders. 21st Century Cures is moving swiftly, now after 1 ½ years of “good and hard bipartisan work”. They came out with a draft in February and have been refining to make it a more bipartisan product. Committee activity will resume on the bill with a legislative hearing on 21st Century Cures on Thursday April 30th (details below). The second draft will be released this week. The bill will be marked-up in the Health Subcommittee and then in full committee with the goal of sending it to the floor by Memorial Day. Rep. Upton’s (R-MI) main concern thus far is making the bill about patients.

When asked how advocates can get involved, Carly responded that “It is important to us to know that you all are involved. I can’t even express how important it is for each of YOUR congressmen and women to know about the initiative and know that you are very supportive of it. It is an extremely powerful messaging tool for us.”

Community Action Alerts

Take Action to Protect Incentives for Rare Disease Drug Development

Kids v. Cancer is seeking organizations to sign-on to two legislative initiatives. The Advancing Hope Act would permanently reauthorize the Priority Review Voucher program, a government incentive that has played a critical role in fostering the development of rare disease treatments. In addition, they are seeking organizations to endorse the Kids Innovative Drugs Initiative, which will reform existing legislation to help ensure that kids are able to access promising therapies. To learn more and to endorse, visit the [Kids v. Cancer homepage](#).

Take Action to Support Increased Funding for NIH and Health Research

The Coalition for Health Funding (CHF) is seeking organizations to sign-on to a [letter](#) to Congress calling for greater funding for health agencies, including the NIH. Every year, Congress must make critical decisions about the funding levels for various federal agencies and departments, but need to hear from health advocates if we want to see meaningful increases in health funding. To sign-on to the letter, fill out this [endorsement form](#).

Endorse the Cure the Process 2 Campaign to Accelerate Rare Disease Innovation

The EveryLife Foundation for Rare Diseases has launched its Cure the Process 2

campaign! The campaign has three goals: 1) to create incentives to encourage companies to repurpose therapies for rare disease patients 2) to enable the FDA to have the in-house experts needed to review rare disease therapies in development 3) to rationalize the clinical trial process in the U.S. to help rare disease patients access to clinical trials. Learn more at the [Cure the Process website](#) and please take a few moments to [endorse the campaign](#). The previous campaign had over 200 endorsing organizations!

Rare Disease Legislation News

New Bill Introduced to Speed Introduction of European Drugs to U.S.

Reps. Tim Ryan (D-OH) and Steve Stivers (R-OH) have introduced a bill, Speeding Access to Already Approved Pharmaceuticals Act, to help bring approved treatments from Europe to U.S. patients. The bill aims to minimize "drug lag", the time delay between when a product is approved in one country and when it is then approved in another. Check out this [article](#) to learn more about the legislation.

Rare Disease Community News & Events

Upcoming Rare Disease Caucus Briefing: 21st Century Cures

On Thursday, May 21st, RDLA will convene a caucus briefing highlighting the priorities for the rare disease community in the 21st Century Cures Initiative. The briefing will feature remarks from Reps. Gus Bilirakis (R-FL) and Leonard Lance (R-NJ), as well as leading policy experts who will discuss various provisions in the draft bill. The event will be held at 12:30pm in the Rayburn House Office Building in room B318 - [click here to register](#).

Legislative Hearing on 21st Century Cures

On Thursday, April 30th at 10:00am, the House E&C Committee will convene a hearing on 21st Century Cures in Rayburn House Office Building, Room 2123. For more information or to live stream the hearing, [visit the E&C website](#).

Senate Hearing - Continuing America's Leadership: The Future of Medical Innovation for Patients

On Tuesday, April 28th at 10:00am the Senate HELP Committee will hold a hearing with top officials from the NIH and FDA. The hearing will be held in the Room 430, in the Dirksen Senate Office building. [Visit the HELP website for more information](#).

Senate Hearing - Committee on Appropriations NIH Budget

On Thursday, April 30th at 10:00am, the Labor, Health and Human Services and Related Agencies Subcommittee (LHHS) will hold a hearing to review the NIH budget for fiscal year 2016. The panel will include Dr. Francis Collins and several institute leaders. [Visit the Appropriations website for more information](#).

May RDLA Meeting

Our next meeting will be held on Wednesday, May 20th at noon in Washington DC. You

may attend in-person or join via webinar. Stay tuned for an invitation.

Save-the-Date for In-District Lobby Days and Regional Events

RDLA's [In-District Lobby Days](#) are right around the corner! Stay tuned for information on registering to meet with your representatives in-district. In addition, RDLA will be holding two regional advocacy conferences during the month of July - one in San Francisco scheduled and another in New Jersey. More information on these events will be included in the next E-blast.

***This E-Blast shares action alerts, legislative, and policy news and events from the patient advocacy community. RDLA does not take positions on the issues herein, but serves as a supportive clearinghouse for the rare disease community. Send us an email if you'd like your alerts and/or events included! Email mbronstein@everylifefoundation.org