



National Health Council

1730 M Street NW, Suite 500, Washington, DC 20036-4561 • 202-785-3910 • www.nationalhealthcouncil.org • info@nhcouncil.org

Game-Changing Dormant Therapies Dropped from 21st Century Cures

Draft Bill Includes Other Provisions Championed by Patients

Washington, DC (May 13, 2015) – The National Health Council (NHC) said it is extremely disappointed that the House Energy and Commerce Committee could not reach a workable compromise to enhance the development of better treatments and new cures for people with unmet medical needs, such as ALS, Alzheimer’s, and lupus.

The concept of dormant therapies, a new classification for drugs that lack patents and those requiring long and arduous clinical trials, was developed by patient organizations representing people with chronic conditions. The Committee had included dormant therapies in early drafts of its 21st Century Cures initiative, but stripped it from the draft legislation released today when Democrats and Republicans could not agree on language.

NHC Chief Executive Officer Marc Boutin issued the following statement:

“The patient advocacy community thanks Committee Chairman Fred Upton (R-MI) and Committee Member Diana DeGette (D-CO) for their tireless work to present a bipartisan bill. However, we believe the Committee has missed a huge opportunity to include a game-changing dormant therapies provision that could have revolutionized the development of treatments desperately needed by people with long-term, life-threatening conditions.

“The NHC supports the provisions of this legislation that advance the discovery and development of treatments, such as the incorporation of patient experience data, improved data sharing of patient information, streamlining the institutional review board (IRB) process for multi-site clinical research, and increased funding for the National Institutes of Health. We will work with Members in both Chambers in our never-ending fight for new, innovative strategies to better meet the health needs of people with chronic diseases and disabilities.

“Though we are extremely disappointed that the Committee did not include dormant therapies in the draft legislation, the patient advocacy community will continue to call for an open, honest, public debate on incentivizing the creation of new treatments. Too many men, women, and children have died waiting for cures for us to give up now.”

For more information:

- NHC and 38 other patient organizations supported the inclusion of dormant therapies in the 21st Century Cures initiative:
<http://www.nationalhealthcouncil.org/sites/default/files/Dormant-Therapies%20Sign-On.pdf>

(more)

Game-Changing Dormant Therapies Dropped from 21st Century Cures

May 13, 2015
Page Two

About the National Health Council:

Founded in 1920, the [National Health Council](#) (NHC) is the only organization that brings together all segments of the health community to provide a united and effective voice for the more than 133 million people living with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes the nation's leading patient advocacy organizations, which control its governance. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, health insurance, medical device, and biotechnology companies.

Contact:

Nancy Hughes
nhughes@nhcouncil.org
Cell: 703-608-9709