Rare Disease Legislation in the Queue

Appropriations: Funding for the National Institutes of Health (NIH) and Food and Drug Administration (FDA)

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Research!America
Fiscal Year 2017 & 2018 Appropriations
Research!America’s Mission

making research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Legislative Process: The Theory
Congress receives the President’s budget.

According to the Constitution, spending bills must originate in the House. In actuality, the House and Senate have their respective budget committees work concurrently on setting an overall budget, as well as spending by budget function (for example, “Health”). If the bills passed by the House and Senate differ, a conference committee then negotiates the difference.

Again, House and Senate appropriations committees work concurrently to determine funding for specific departments and agencies. This work is done by subcommittees specific to areas like science and health. If the final appropriations bills differ, a conference committee again negotiates the difference.
Congress receives the President's budget.

March

April

6 mos. before new fiscal year

May

June

July

August

September

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October

New fiscal year begins Oct. 1

Appropriations bills are sent to the President for signature. This is supposed to be done by Oct. 1, the start of the fiscal year, but it is uncommon. Congress more often passes a continuing resolution (CR) to fund the government while it finishes the budget.

The budget is complete and agencies receive their funding.
Legislative Process: The Reality
Appropriations Leaders

Sen. Thad Cochran  (R-MS)  
Chair

Sen. Patrick Leahy  (D-VT)  
Ranking Member

Rep. Rodney Frelinghuysen  (R-NJ-11)  
Chair

Rep. Nita Lowey  (D-NY-17)  
Ranking Member

Senate Appropriations  
House Appropriations
Appropriations Status - FY17

• Continuing Resolution through 4/28/2017
• Next Steps? Continuing Resolution through 9/30/17 or Omnibus
• Labor, Health and Human Services, and Education Appropriations (Labor/HHS)
Appropriations Asks - FY18

Our Asks:

• $2B increase for NIH
• $2.8B increase for FDA
• Appropriators release the targeted FY18 Innovation fund dollars for NIH and FDA included in the 21st Cures Act
Why NIH and FDA

**NIH**

World’s largest public funder of biomedical research, investing funding appropriated by Congress to enhance life, reduce illness and disability

**FDA**

Responsible for protecting and promoting public health through the control and supervision of food and drug products
21st Century Cures
History

• Championed in the House by Rep. Fred Upton (R-MI), Chair, House Energy and Commerce Committee, and Rep. Diana DeGette (D-CO) and in the Senate by Sen. Richard Burr (R-NC) and Sen. Lamar Alexander (R-TN)

• Examine the full arc of the discovery, development, and delivery process for treatments and cures in America

• Final Passage: December 7th, 2016
Advocacy Works

• Propelled medical progress into the spotlight

• Collaborative legislative model that brings patients to the table with policymakers, industry, researchers, and other advocates

• Demonstrates that better health transcends partisanship, civility is a possibility, and gridlock need not be the rule

• Connects the dots between discovery, development and delivery

“Bipartisan passage of the 21st Century Cures Act is a victory for patients and their loved ones – and that ultimately means all of us...”

Statement by Research!America President and CEO Mary Woolley on Passage of 21st Century Cures Act (HR 6)

July 10, 2015
Highlights of Legislation

• Funding research to drive bold initiatives like the Cancer Moonshot
• Incorporating the patient voice into drug development
• Improving U.S. mental health infrastructure and funding solutions to the opioid crises
• Supporting the next generation of researchers
• Cutting red tape to get scientists back in the lab
• Taking steps to combat antimicrobial resistance
Appropriations for Cures - FY17

- Fiscal Year 2017 Continuing Resolution Provided:
  - $352 million for the NIH initiatives
  - $20 million for FDA
  - $500 million for states to respond to the opioid abuse crisis
Appropriations for Cures - FY18

• Fiscal Year 2018 Continuing Resolution for NIH Innovation Projects:
  • Precision Medicine Initiative $100,000,000.
  • Brain Initiative $86,000,000.
  • Cancer Moonshot $300,000,000.
Implementation

• Funding
  • Advocate for funding for FY18-FY 2026 (appropriations)

• Hiring
  • Ensure FDA has sufficient staffing resources

• Guidance Documents
  • Follow regulations.gov for guidance documents and notices of public meetings
Learn More

• https://energycommerce.house.gov/cures
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Thank You!

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