Welcome to Washington!

“Every public health decision is made on a political decision.”

William Foege, MD, MPH
Senior Fellow, Bill & Melinda Gates Foundation; Former Director, CDC
Advocacy Works!

2015 was a very busy year....

- Meaningful increase in FY16 funding for medical research
- Medical device tax paused until FY18
- A permanent R&D tax credit
- Agency for Healthcare Research and Quality preserved
Science and Public Health at Risk puts our Nation at Risk

- Appropriations process is stalled; Congress may flat-fund the government for the remainder of FY17
- Zika funding late and inadequate; other examples
- Sequestration (which places an artificially low ceiling on federal spending) is back next year after a two year “pause”
- Medical device excise tax returns end of 2017
- 21st Century Cures is still not law
Gasping for Breath

- **21st Century Cures Initiative (House E&C Committee)**
  - Legislation to refine the discovery, development and delivery pipeline and provide supplemental funding to accelerate medical progress.
  - Resulted in 21st Century Cures Act (H.R. 6)
    - Passed the House of Representatives in July 2015 with broad bipartisan vote of 344-77
    - Includes 5 years mandatory funding for NIH ($1.75b/yr) and FDA ($550m/yr) over appropriations
- **Innovation Initiative (Senate HELP Committee)**
  - Companion process to 21st Century Cures Act; HELP Committee passed 19 separate bills that largely mirror provisions in HR 6
  - House and Senate leadership negotiating compromise package for consideration during “lameduck” session of Congress
Current Advocacy Agenda

- Prevent a long-term “continuing resolution” that flat-funds government for the remainder of FY17.
- Secure robust increases for NIH, FDA, CDC, AHRQ, and NSF in FY17 and FY18
- Provide input to presidential transition teams
- Secure passage of compromise 21st Century Cures Act
- Protect health services research (HSR) and social, behavioral, economic (SBE) research from ongoing threats of budget cuts
- Build champions for research in Congress
- Push for establishing a standing public health emergency fund to empower faster response to emerging health threats like Zika
- Push for permanent repeal of medical device excise tax
Current *Context* for Advocacy

- Questioning of all public expenditures
- Importance of job creation, economic growth and competitiveness
- Election-year politics
- Cost and access questions can crowd out other health issues, including research
- Scientists are invisible in our society
- History points to importance of patient advocacy
- Elevate medical research in the national conversation during the election season
- Encourage voters to ask candidates their views on issues affecting the pace of medical progress
- Increase public awareness of how public and private sector research contributes to the health and economic security of our nation

Visit [www.campaignforcures.org](http://www.campaignforcures.org) for more information!

[Twitter.com/Campaign4Cures](https://twitter.com/Campaign4Cures)
[Facebook.com/Campaign4Cures](https://facebook.com/Campaign4Cures)
Campaign for Cures

Research!America recently launched an online interactive map of candidates’ views on medical progress where visitors can view more than 500 quotes on issues related to public and private sector research and innovation from candidates who win their state primaries.

The Campaign for Cures blog features election news, survey data, commentary and analysis of the presidential race and congressional races in key states on topics relevant to medical progress.
“Advancing science and technology will be among my highest priorities as President...I share the concerns of the science and technology community, including many in the industry, that the United States is underinvesting in research. Federal funding of basic research amounts to less than one percent of annual federal spending, yet it is an investment that pays big dividends. I believe it is essential that we strengthen our research capacity, by funding talented young investigators, looking for ways to prioritize “high-risk, high-reward” projects that have the potential to transform entire fields, and enhancing partnerships between government, universities, and the private sector.”

- ScienceDebate.org

Presidential Nominee, Hillary Clinton
“...Scientific advances do require long term investment. This is why we must have programs such as a viable space program and institutional research that serve as incubators to innovation and the advancement of science and engineering in a number of fields. We should also bring together stakeholders and examine what the priorities ought to be for the nation. Conservation of resources and finding ways to feed the world beg our strong commitment as do dedicated investment in making the world a healthier place. The nation is best served by a President and administration that have a vision for a greater, better America.” - Sciencedebate.org

President Nominee, Donald J. Trump
Party Platforms on Research

- DNC platform supports investments in medical research, including “full funding” of NIH; addressing drug addiction and mental health, investing in AIDS/HIV research and global health issues (Zika, Ebola)
- RNC platform supports partnerships among small businesses and federal research agencies, advancing research and development in health care, reforming FDA and combatting drug abuse
Our challenge to would-be advocates: Pass the “Starbucks Test”
“I don’t care if you’re Republican or Democrat, liberal or conservative-- Alzheimer’s and cancer don’t pick people that way....everyone has a personal story. And in a very divided time, a polarized time, people are looking for things to work together on and support, and NIH and CDC are two of those things.”

-- Accepting the Whitehead Award for Medical Research Advocacy during Research!America’s 2016 Advocacy Awards Dinner
“It is critical that we secure and build on the United States’ leadership in medical innovation. To do this, I believe Congress has to look at how we can ramp up investment in the kind of research and development that helps drive this private sector growth.”

Rep. Patty Murray (D-WA), Ranking Member HELP Committee and Ranking Member Labor-H Appropriations Subcommittee
Democrats: 7

Warren Grant Magnuson (D, WA)
• U.S. Rep (1937-1944)
• U.S. Senator (1944-1981)

Lawton Chiles (D, FL)
• U.S. Senator (1971-1989)
• Florida Governor (1991-1998)

Claude Denson Pepper (D, FL)
• U.S. Senator (1936-1951)
• U.S. Representative (1963-1989)

Joseph Lister Hill (D, AL)
• U.S. Representative (1923-1938)
• U.S. Senator (1938-1969)

Dale Bumpers (D, AR)
• Arkansas Governor (1971-1975)
• U.S. Senator (1975-1999)

William Natcher (D, KY)
• U.S. Representative (1953-1994)

Louis Stokes (D, OH)
• U.S. Representative (1969-1999)
• Board Member (2007-2010)

Republicans: 5

Lowell P. Weicker, Jr. (R, CN)
• U.S. Representative (1969-1971)
• U.S. Senator (1971-1989)
• Connecticut Governor (1991-1995)

Mark Hatfield (R, OR)
• Oregon Governor (1959-1967)
• U.S. Senator (1967-1997)

C.W. Bill Young (R, FL)
• U.S. Representative (1971-2013)

John Edward Porter (R, IL)
• U.S. Representative (1980-2001)
• Chair of Research!America

Silvio O. Conte (R, MA)
• U.S. Representative (1959-1991)

*Plaza named for Paul G. Rogers (D, FL, U.S. Representative 1955-1979) Former Chair of Research!America
Research!America’s Mission

Making research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Research!America: 27 Years of Putting Research on the Public Agenda

- Nonprofit alliance with member organizations drawn from academia, business, patient organizations and scientific societies representing more than 125 million Americans
- Distinguished, all-volunteer board includes former elected and appointed officials, media and public relations leaders, and leaders from alliance member organizations
- Three ‘sister’ organizations in Canada, Australia and Sweden
Research!America Board Members (partial list)

- The Honorable John Edward Porter*, Senior Advisor, Hogan Lovells US LLP
- The Honorable Michael Castle*, Partner, DLA Piper, LLP
- E. Albert Reece, M.D., Ph.D., MBA, Vice President of Medical Affairs; University of Maryland School of Medicine
- Hortensia Amaro, Ph.D., Professor of Social Work and Preventive Medicine, University of Southern California School of Social Work
- Georges Benjamin, M.D., Executive Director, American Public Health Association
- William Hait, M.D., Ph.D., Global Head, Janssen Research & Development
- Nancy Brown, CEO, American Heart Association
- Susan Dentzer, President and Chief Executive Officer, Network for Excellence in Health Innovation
- Martha Hill, Ph.D., RN, Dean Emerita, Professor of Nursing, Medicine & Public Health, The Johns Hopkins University School of Nursing
- The Honorable Rush Holt*, Ph.D., CEO, American Association for the Advancement of Science
- Mark McClellan, M.D., Ph.D., MPA, Director, Center for Health Policy, Duke University
- The Honorable Kweisi Mfume*
- Harry Johns, CEO, Alzheimer’s Association
- James Madara, M.D., CEO, American Medical Association
- Keith Yamamoto, Ph.D., Vice Dean for Research, School of Medicine, University of California, San Francisco
- Elias Zerhouni, M.D., President, Global Research & Development, Sanofi

*Former Member of Congress
Research!America Goals

• Achieve funding for research at the level of scientific opportunity
• Advocate for a policy climate that stimulates rather than impedes research and development
• Empower members of the science community to advocate medical and health research
• Ensure that the public hears about research benefits and success stories: Research must not become invisible!
Strategy for Success: Research!America

- Keep a finger on public pulse via public opinion surveys
- Develop and deliver timely messages
- Track investment in research
- Design and trigger grassroots plus grasststops advocacy strategies
- Drive earned and paid media attention
- Engage congressional champions
- Empower members of the science community as advocates
Engaging Congressional Champions

Dr. Mary Hendrix (left), Senator Dick Durbin (D-IL) and Mary Woolley at the 2015 Rally for Research reception. Medical Research!America Vice Chair Hon. Michael Castle and Mary Woolley presented the Edwin C. Whitehead Award for Medical Research Advocacy to Reps. Fred Upton (R-MI) and Diana DeGette (D-CO).
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln
Research!America Surveys

- Commissioning public opinion surveys on research issues for 24 years:
  - National Surveys
  - State-Based Surveys
  - Issue-Specific Surveys
- Online surveys are conducted with a sample size of 1000-2000 adults and sampling error of +/-3.1%. The data are weighted in two stages to ensure accurate representation of the U.S. adult population.
Americans Support Swift Congressional Action on R&D

How important is it that (the current) Congress pass legislation to increase the pace of medical progress?

- Very Important: 43%
- Somewhat Important: 32%
- Not Too Important: 9%
- Not At All Important: 3%
- Not Sure: 14%

Source: A Research!America and ScienceDebate poll of U.S. adults conducted in partnership with Zogby Analytics, September 2015.
Only a Third Believe U.S. Health Care System Best in World

Do you believe the United States has the best health care system in the world?

- Yes: 33%
- No: 50%
- Not Sure: 17%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Americans Split on Whether Health Care is Based on Latest Research

Do you believe the health care services you personally receive are based on the best and most recent research available?

- Yes: 41%
- No: 36%
- Not Sure: 23%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Majority say Important to Invest in Health Care Delivery Research

A type of research called health care delivery research seeks to translate discoveries from research into medical practice. How important do you think it is for the United States to invest in health care delivery research?

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in June 2016.
Nearly Half Say Not Enough Progress in Developing Medicines

Do you believe we are making enough progress in developing new medicines?

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in June 2016.
Seven in 10 Say Practitioners Don’t Talk About Medical Research

Has your doctor or other health care professional ever talked to you about medical research?

- **Yes**: 22%
- **No**: 70%
- **Not sure**: 8%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
Majority willing to share personal data for medical research

For which of the following would you be willing to share your personal health information? (Choose all that apply)

- To advance medical research: 59%
- So health care providers can improve patient care: 56%
- So public health officials can better track diseases and disability and the causes: 46%
- None: 14%
- Not Sure: 12%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Improving Others’ Health Important for Participation

How important would the opportunity to improve the health of others be in your decision to participate as a volunteer in a clinical trial?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
Important to Conduct Research to Eliminate Health Disparities

Studies show that certain health problems such as diabetes, heart disease, and infant mortality happen more often among minorities or citizens with lower incomes. How important do you feel it is to conduct medical or health research to understand and eliminate these differences?

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
“If you think research is expensive, try disease.”

Mary Lasker
1900-1994
Effective Communications

Keep your communications efforts local, simple, constant, and relatable.

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**Investment in research saves lives and money**

**Cancer**

Today:

- In the U.S., it is estimated that more than 1.6 million people diagnosed with cancer in 2020, with the American mortality of 29.8 deaths per 100,000 persons.
- As the second-leading cause of death in the U.S., cancer kills more people than heart disease.
- In 2019, 1.7 million men and women died of cancer, or 1,223,000 deaths (647,000 men and 576,000 women).
- Cancer death rates are highest among African Americans, followed by Hispanics, Native Americans, and Alaska Natives.

**How research saves lives and money**

Over the past 10 years, mortality rates for childhood cancer have been reduced significantly, dropping 35% during this time period due to advances in treatment and technology.

- The study funded by the National Cancer Institute, among other insurance cancer patients receiving a bone marrow transplant, shows that those who received the transplant within 30 days after the diagnosis had a better survival rate compared to those who received the transplant more than 30 days after the diagnosis.

**How research saves money**

- The National Cancer Institute (NCI) has invested over $1 billion in cancer research in the past year, leading to new discoveries and treatments. The NCI has doubled its investment in cancer research since 2000, and now spends over $11 billion annually on cancer research.

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**Dubuque News Tribune**

**Reader's view: Federal funding needed for biomedical research**

By Steve Haggerty, on May 17, 2023

In his June commentary in the News Tribune, headed, “To remain global leader, U.S. must invest in biomedical research,” Minnesota Sen. Amy Klobuchar made a strong case for increased federal funding for biomedical research.

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**The Michigan Daily**

**Scientific leaders make policy recommendations to University**

By Ian Dillingham, Statement Editor

Published March 31, 2015

Scientific leaders are looking to lay the groundwork for new science policy initiatives at the University and beyond. The exploration of initiatives was discussed at the Jerome B. Wiesner Symposium on Tuesday.

The two-day event at Rackham Amphitheatre brought together some of the nation’s leading scientific minds and policymakers to discuss the current state of scientific research. During the symposium, attendees created a series of recommendations for the
Aspirational Communications

THEN...
Between 1918-1919, more than 500,000 persons in the U.S. died of influenza.

NOW...
Almost 60% of children and 44% of adults received a flu vaccine in 2015.

IMAGINE...
No deaths from influenza.

Sources: Nursing Forum Vol.25, No. 2, 1990; Nursing World, Sept 2015; CDC
THEN... In 1975, just over 50% of children diagnosed with cancer survived the disease.

NOW... Due largely to evidence-based advances in treatment of the most common forms of childhood cancer, more than 80% of children survive cancer.

IMAGINE... If cancer no longer robbed any child of their future.

Research is the future!
The combined salaries of the top ten highest-paid athletes in 2015 totaled more than $610 million.

That amount is enough to fund all NIH-sponsored head and spine injury research for more than 3 years.

Sources: Forbes, NIH
- The Department of Homeland Security’s budget in 2016 totals $41.2 billion.

- Health Security: The National Institutes of Health budget in 2016 is $32.3 billion.

Sources: DHS, NIH
Research is Invisible
Can Americans Name a Living Scientist?
Most Americans Cannot Name a Living Scientist

Can you name a living scientist?

I can

17%

Stephen Hawking (40%)
Neil deGrasse Tyson (15%)
Jane Goodall (7%)
Bill Nye (6%)
Michio Kaku (4%)
Richard Dawkins (4%)
James Watson (2%)
Ben Carson (2%)
Other (20%)

I cannot

83%
Do Americans Know Where Research is Conducted?
Most Americans Don’t Know Where Research is Conducted

Can you name any institution, company or organization where medical or health research is conducted?

- 34% I can
- 66% I cannot

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.

Mayo Clinic (25%)
Johns Hopkins University (19%)
St. Jude Children’s Research Hospital (6%)
UCLA (5%)
NIH (5%)
Duke University (4%)
CDC (4%)
Sloan Kettering (3%)
Other (29%)
Is it Important for Scientists to Communicate with the Public?
How important is it for scientists to inform elected officials and the public about their research and its impact on society?

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
WARNING: Failure to be an advocate can be hazardous to your research career.
What do scientists, elected officials, and journalists have in common?
Serving the Public’s Interest
What Can You Do?

- Talk about aspirations for better health, and talk about return on investment in research
- Use in-the-moment news to illustrate public aspirations for better health
- Emphasize how research drives economic activity in every state and creates good jobs
- Convey your personal commitment
- Encourage your colleagues to engage non-scientists
- Support the 21st Century Cures initiative
- Take the Campaign for Cures pledge

[www.campaignforcures.org](http://www.campaignforcures.org)
Put a Face on Research: YOURS!
Remember the most important four words a researcher can say and convey:
Connect with Research!America Online

- www.researchamerica.org/blog
- www.researchamerica.org/facebook
- www.twitter.com/researchamerica
- www.youtube.com/researchamerica