Advocacy in Uncertain Times

Mary Woolley, President and CEO, Research!America

Oct. 17, 2017
Washington, DC
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
Thoughts: Working on the Hill

• Bipartisanship is possible!

• The front desk staff have the hardest job, be kind to them

• When meeting with your member’s constituents, it is okay to say you do not know and get back with them

• Very few Hill staff have a public health or any science background; you will be almost unique and could be sought-after

• The meticulousness needed for a staffer’s job is not much different from working with data sets or in a lab or clinic

• The most valuable staffer is the one eager to take on any task
Today’s Research Advocacy Landscape

Opportunities:

• March for Science revealed untapped advocacy potential
• Strong leadership in Congress for medical and health research
• Science aligns with many Administration objectives, including job creation, economic growth and global competitiveness

Challenges:

• Skepticism by some in Congress about accuracy of climate science compromises our nation’s role in advancing “one health” and responding to health threats related to climate change
• The White House has placed a bullseye on the “F & A,” or “indirect” costs of research. Congress is blocking the OMB “10% cap” proposal, but is holding hearings on the issue that could provoke detrimental policy changes
• “Labor-H” appropriations bills target stem cell and fetal tissue research
• Behavioral and social science is undervalued and often attacked
Federal Funding State of Play

- Government funded by a Continuing Resolution until December 8, 2017
- The FY18 budget cap on non-defense discretionary (NDD) spending is $3 billion lower than in FY17, which means difficult budget tradeoffs if allowed to stand
- Advocates must urge Congress to make a bipartisan budget deal to raise the budget caps. If they fail to do so, NIH is still likely to receive an increase in FY18, but in the $1 billion range instead of $2 billion. FY19 could be far worse.
- Absent a budget deal, other health and science agencies will undoubtedly receive budget cuts in FY18 and FY19.
September 20, 2017

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Charles Schumer
Minority Leader
U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

Dear Majority Leader McConnell and Minority Leader Schumer,

On behalf of Research!America, the nation’s largest not-for-profit alliance working to accelerate medical progress and strengthen our nation’s public health system, I urge you to reject any attempt to reduce or eliminate the Prevention and Public Health Fund.

It is counter to the interests of our nation to reduce this pragmatic, fiscally responsible fund, with its emphasis on stopping deadly and costly diseases before they rob Americans of independence, resources, and time. Analyses of economic outcomes have consistently concluded that prevention programs can save significant amounts of money in the short- and long-term. Looking at Alzheimer’s disease alone, a delayed onset of disease for five years would result in annual savings totaling $376 billion by 2050. The Prevention and Public Health Fund provides resources for prevention programs throughout the country spanning a wide array of conditions, including heart disease and stroke, substance abuse, obesity, cancer, lead poisoning, suicide and diabetes.

The fund also provides resources for vital infectious disease surveillance and response systems, which allow communities to better prepare and protect their citizens. And it is being used to reduce health care-associated infections, which take the lives of tens of thousands of Americans each year. The benefits of the PPHF extend far beyond these examples, but they are indicative of its positive impact.

We firmly believe that whether the goal is to advance the well-being of Americans or reduce the nation’s health care costs, the elimination of the Prevention and Public Health Fund runs counter to those goals. It is imperative that the Prevention and Public Health Fund is preserved.

Thank you for your leadership and your stewardship for our nation’s priorities.

Sincerely,

Mary Woolley
President and CEO

Prevention and Public Health Fund

- Research!America’s letter to Senate leadership on the importance of the Prevention and Public Health Fund (PPHF)
Overall *Context* for Advocacy

- Questioning of all public expenditures
- Importance of job creation, economic growth and competitiveness
- 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
A Challenge: 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

Rep. Tom Cole (R-OK-04), Chairman, Labor-H Appropriations Subcommittee
“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: 28 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 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 for 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 grasstops advocacy strategies
- Drive earned and paid media attention
- Engage congressional champions
- Empower members of the science community as advocates
“...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.
How important do you think it is that the U.S. is a global leader in medical, health and scientific research?

65% Very important
26% Somewhat important
5% Not too important
2% Not at all important
3% Not sure

Majority Do Not Believe U.S. Health Care is World’s Best

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

- Yes: 54%
- No: 30%
- Not sure: 16%

Opinions Split on Whether Health Care Based on Best Available Research

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

- 40% Yes
- 40% No
- 20% Not sure

The U.S. Should 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?

Many Support Increased AHRQ Funding

The Agency for Healthcare Research and Quality (AHRQ) is the federal agency charged with funding health care delivery research, which seeks to rapidly translate discoveries from research into medical practice and improve the quality, safety and effectiveness of health care. Which of the following statements most accurately reflects your view?

- Funding for AHRQ is not a priority (19%)
- AHRQ funding should be increased as a strategy to improve health care quality and safety in the U.S. (42%)
- Don't know/no opinion (39%)

Majority say Funding for CDC Should Increase

The Centers for Disease Control and Prevention (CDC) works to protect America from health, safety and security threats, both foreign and in the U.S. How important is it to increase funding for the CDC?

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
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?

Important for Elected Officials to Listen to Scientists

How important is it that elected officials at all levels listen to advice from scientists?

- 52% Very important
- 32% Somewhat important
- 5% Not very important
- 2% Not important at all
- 10% Not sure

“If you think research is expensive, try disease.”

Mary Lasker
1900-1994
Research is Invisible
Despite High Levels of Public Confidence, Scientists are Invisible in Our Society...
Can Americans Name a Living Scientist?
Most Americans Cannot Name a Living Scientist

Can you name a living scientist?

- Stephen Hawking (27%)
- Neil deGrasse Tyson (19%)
- Bill Nye (5%)
- Richard Dawkins (3%)
- Jane Goodall (2%)
- Anthony Fauci (2%)
- Michio Kaku (2%)
- Me (2%)
- James Watson (1%)

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?

- 33% I can
  - Mayo Clinic (17%)
  - Johns Hopkins University (10%)
  - St. Jude Children’s Research Hospital (6%)
  - NIH (4%)
  - Cleveland Clinic (4%)
  - MD Anderson Cancer Center (2%)
  - Harvard University (3%)
  - American Cancer Society (2%)
  - CDC (1%)

- 67% I cannot

Most Americans Don’t Know Research is Conducted Nationwide

To the best of your knowledge, would you say that medical research in the U.S. is conducted in all 50 states?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Is it Important for Scientists to Communicate with the Public?
Important for Scientists to Engage with Public on Research

How important is it for scientists to inform elected officials and the public about their research and its impact on society?

- **60%** Very Important
- **26%** Somewhat Important
- **5%** Not Very Important
- **7%** Not Important At All
- **2%** Not Sure

**Source:** A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in July 2017.
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 regularly
Effective Communications

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

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**Letters Scientists Must Speak Up**

Robert Thorson’s column [April 17, 2017, content.com, “Trump Cuts Sending Scientists To Streets”] brilliantly highlights many examples of science’s enduring contributions to society. That’s why it is more important than ever as policy makers debate funding for research and funding for science and what it can produce to benefit future generations.

A majority of Americans agree the knowledge scientists should speak up and not stop working.

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**If we want this nation to succeed, we can’t put facts up for dispute**

Regarding the ADB’s next article “Is the US less resiliently question science education?”,

Our nation was built on the pursuit of knowledge. In which teachers and students are free to accept their own education, study and evaluate ideas, including environmental ones. But, over recent years science has been shown to be far less effective and students in this model do not get engaged in unique, such as observation and intelligent design. Procedural knowledge must continue to support the evidence and our empirical future supported by continuous and scientific investigations that generate and test ideas that contradict the knowledge base.
THEN... 130,000 new cases of HIV infection occurred annually in the U.S. during the peak of the AIDS epidemic in the 1980s, and most cases were fatal.

NOW... (thanks to research) The development of Highly Active Antiretroviral Therapy (HAART), revolutionized the battle against HIV/AIDS and transformed the virus from a death sentence to a manageable chronic condition.

IMAGINE...(thanks to research) A universal HIV vaccine and complete eradication of HIV/AIDS, worldwide.

Research is the solution to what ails us!
THEN...
Between 1918-1919, more than 500,000 persons in the U.S. died of influenza.

NOW...
Almost 60% of children and 42% of adults received a flu vaccine in 2016.

IMAGINE...
No deaths from influenza.

Research is the solution to what ails us!

Sources: Nursing Forum Vol.25, No. 2, 1990; CDC
In 2016, the 32 teams in the National Football League are worth an estimated $62.9 billion.

That amount could fund NIH-sponsored neuroscience research for up to 9 years!
A Nation Worth Defending

- U.S. defense spending in 2016 totaled $585 billion.

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

“The NIH... is our nation's Department of Defense for America's personal health”*

Sources: DHS, NIH, Congressman Steve Cohen* (D-TN)
On November 20, Research!America and leading public health organizations will take time to recognize public health professionals who work tirelessly every day to protect us from disease, injury, and other health threats.

Join us in thanking public health professionals in your communities.

Visit [www.publichealththankyouday.org](http://www.publichealththankyouday.org) to learn more and join the conversation!
Put a Face on Research: YOURS!
Remember the most important four words a researcher can say and convey:
“I work for you.”
Connect with Research!America Online

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