Turning a Moment Into a Movement: Advocacy for Medical and Health Research

Mary Woolley, President, Research!America
“Every public health decision is made on a political decision.”

William Foege, MD, MPH
Senior Fellow, Bill & Melinda Gates Foundation; Former Director, CDC
Science and Public Health at Risk in the U.S.

- Sequestration is back after two year “pause;”
- A deal to lift sequestration caps temporarily or permanently is a long-shot;
- Senate FY 2016 “Labor-H” bill cuts CDC funding by 4% and AHRQ by 35%; House bill eliminates AHRQ altogether. NIH fares better than in FY15.
- A year-long CR (possible) would further erode agencies’ purchasing power
- Congress is once again kicking the can down the road on tax and policy decisions
Science and Public Health at Risk in the U.S. (cont.)

- Policymakers attacking fetal tissue and health economics/social sciences research
- Science skepticism apparent in vaccination issue; “Right to Know” campaigns, and climate change
- Young scientists are understandably disillusioned; turning away from science
- The science community is essentially invisible to the public and policymakers
A Breath of Fresh Air

- **21st Century Cures Initiative (House E&C Committee)**
  - Year-long process to gather information from experts, including advocates
  - Resulted in 21st Century Cures Act (H.R. 6)
    - Reported out of E&C Committee by rare unanimous vote
    - Passed the House of Representatives in July 2015 with broad bipartisan vote of 344-77
    - H.R. 6 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; now in information gathering and legislation drafting phases
  - Legislative draft to be released shortly
  - Not likely to include mandatory funding for NIH and FDA
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 One Third Say U.S. Will Be a Science Leader in 2020

In your view, which of the following will be considered the number one world leader in science and technology in the year 2020?

- United States: 36%
- China: 26%
- India: 5%
- European Union: 4%
- Brazil: 1%
- Not sure: 29%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in August 2014.
Only 39% Say U.S. Will Be a Leader in Health Care in 2020

In your view, which of the following will be considered the number one world leader in health care in the year 2020?

- United States: 39%
- China: 5%
- India: 2%
- European Union: 20%
- Brazil: 1%
- Not sure: 33%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in August 2014.
Do you believe that the health care services you receive are based on the best and most recent research available?

- Yes: 46%
- No: 32%
- Not sure: 22%

Source: A Research-America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
How important is it that the federal government funds research that identifies ways to help our health care system function more effectively and efficiently?

- Very important: 49%
- Somewhat important: 32%
- Not very important: 6%
- Not at all important: 4%
- Not sure: 9%

Source: A Research!America and ScienceDebate poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Research!America’s Mission

Make research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Research!America: 26 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
Research!America Goals

- Achieve funding for research at the level of scientific opportunity
- Advocate 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!
Our Vision

Achieve national commitment to pursuing medical and health research at the highest level of scientific opportunity in both the public and private sectors, to assure medical progress.
Strategy for Success: Research!America

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

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).

Dr. Mary Hendrix (left), Senator Dick Durbin (D-IL) and Mary Woolley at the 2015 Rally for Research reception. Medical
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
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

Abraham Lincoln
Research!America Polling

- Commissioning public opinion polls on research issues for more than 22 years:
  - National Polls
  - State-Based Polls
  - Issue-Specific Polls
- Telephone (random-digit dialing) polls are conducted with a sample size of 800-1000 adults (age 18+) and a maximum theoretical sampling error of +/- 3.5%. Data are demographically representative of adult U.S. residents (state or national).
- Online polls 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.
Do you believe that we are making enough progress in medical research in the U.S.?

- Yes: 39%
- No: 48%
- Not sure: 13%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
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?

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

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
Americans Willing to Share Personal Health Data for Research and Patient Care

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

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>So health care providers can improve patient care</td>
<td>60%</td>
</tr>
<tr>
<td>To advance medical research</td>
<td>55%</td>
</tr>
<tr>
<td>So public health officials can better track disease and disability and the causes</td>
<td>46%</td>
</tr>
<tr>
<td>None</td>
<td>10%</td>
</tr>
<tr>
<td>Not Sure</td>
<td>13%</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Not very important</th>
<th>Not at all important</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
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<td>62</td>
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<td>7</td>
<td>5</td>
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<tr>
<td>Asian</td>
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<td>38</td>
<td>5</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
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<td>30</td>
<td>6</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>49</td>
<td>38</td>
<td>7</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

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?

- **Very Important**: 34%
- **Somewhat Important**: 5%
- **Not Too Important**: 13%
- **Not At All Important**: 5%
- **Not Sure**: 13%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Effective Communications
Localized Communications
Localized Communications, cont.
Simplified Communications
“If you think research is expensive, try disease.”

Mary Lasker
1900-1994
Letters to the Editor

Letter: Senate must act on bill to advance research

In response to the July 15 News editorial, “Bipartisanship legislation will provide an overdue boost for medical innovation,” House passage of the 21st Century Cures Act is a significant development for patients and researchers alike as many members of Congress demonstrate their determination to support research and medical innovation.

Reader’s view: Federal funding needed for biomedical research

To her June 27 commentary in the News Tribune, headlined, “To remain global leader, U.S. must invest in biomedical research,” Minnesota Sen. Amy Klobuchar was on point in terms of the necessity of robust and sustained federal funding for biomedical research to maintain our global leadership in science and innovation.

A Bill to Fast-Track Drug Approval

To the Editor:

In “Don’t Rush Drugs to Market” (Op-Ed, June 11), Gregg Gonsalves, Mark Harrington and David A. Kessler suggest that the pending 21st Century Cures Act would open the door to lower standards for approval by the Food
Op-Eds

Research in academic medical centers: Two threats to sustainable support

ROLL CALL

A Worthy New Year's Resolution for the New Congress

Saving Lives in the 21st Century and Beyond | Commentary

By Mary Woolley

New technology such as CRISPR-Cas9, a genuine scientific breakthrough, is raising hope for patients with cancer, cystic fibrosis, sickle-cell anemia and other major health threats. The gene editing tool, used in precision medicine, allows changes to be introduced into the DNA of any human cell — potentially enabling repair of disease-causing mutations, neutralization of...
THEN... 130,000 new cases of HIV infection occurred annually during the peak of the AIDS epidemic in the 1980s, and most cases were fatal.

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

IMAGINE... A universal HIV vaccine and complete eradication of HIV/AIDS.

Research is the future!
“Without research, there is no hope.”

The Hon. Paul G. Rogers (1921-2008), Emeritus Chair, Research!America
In 2013, National Football League teams split $6 billion in revenue.

That amount is enough to fund NIH sponsored traumatic brain injury research for 68 years!

Sources: CBS; NIH FY2013
Relatable Communications

AKA Social Math

- In 2014, Americans spent $48 billion on sporting goods.

- That amount is more than the combined budgets for the National Institutes of Health, the Centers for Disease Control and Prevention, and the Food and Drug Administration.

Sources: IBIS World. American Association for the Advancement of Science.
Research is Invisible
Can Americans Name a Living Scientist?
Most Americans Can’t Name a Living Scientist

Please name a living scientist.

- I can
  - Stephen Hawking: 43%
  - Neil Degrasse Tyson: 6%
  - Bill Nye: 5%
  - Jane Goodall: 5%
  - James Watson: 3%
  - Richard Dawkins: 2%
  - Michio Kaku: 2%
  - Mehmet Oz: 1%
  - Other: 33%

- I cannot

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
Do Americans Know Where Research is Conducted?
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 2015.
Most Americans Don’t Know Where Research is Conducted

Please name any institution, company or organization where medical or health research is conducted.

- Mayo Clinic: 14%
- Johns Hopkins: 14%
- CDC: 8%
- NIH: 6%
- Pfizer: 4%
- Cleveland Clinic: 3%
- St. Jude’s: 2%
- American Cancer Soc.: 2%
- Harvard University: 2%
- Duke University: 1%
- Eli Lilly: 1%
- Other: 43%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
Is it Important for Scientists to Communicate with the Public?
EMBARGOED: Important for Scientists to Communicate with 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 poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
“Connecting the Dots: Effectively Communicating Science to Non-scientists”

Regular workshops for scientists across the country.

Pictured: Frank Sesno conducts mock interview as part of April 2015 workshop conducted in partnership with George Washington University.

Recent Partners:
Put a Face on Research: YOURS!
Remember the most important four words a researcher can say and convey:
“I work for you.”
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