World Class Advocacy for World Class Research

Mary Woolley, President, Research!America
Advocacy works!

• Now it’s time to turn last year’s ‘moment’ for research into a movement
• Advocates for each sector working to achieve medical progress must stand shoulder-to-shoulder for research in 2016
• Scientists must be more visible and accountable
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 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 stakeholder community to engage non-scientists & advocates for research
• Ensure that the public hears about research benefits and success stories: Research must not become invisible!
Simplest of Messages

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

Mary Lasker
1900-1994
Career Commitment to Advocacy for the NIH

- 1972: Joined San Francisco site of then-largest-ever NIH-funded clinical trial
- Later became CEO of the Medical Research Institute of San Francisco
- President and CEO of Research!America since 1990
The NIH in 1972

- Total NIH funding: $1.506 billion
- In 1972, NIH consisted of 15 institutes and centers; today there are 27
- Current institutes and centers that didn’t exist in 1972:

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“Scientists must take off their lab coats and engage the people of their communities and states. They must be willing to defend and spread the good news about science.”

*Science* magazine editorial, June 2014
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)

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)

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

*Plaza named for Paul G. Rogers (D, FL, U.S. Representative 1955-1979)
Return on Investment

- Initial $4 billion HGP investment led to economic impact of $796 billion, created 310,000 jobs
- The resulting industry generated $6 billion in federal, state and local taxes in 2010

Sources: “Economic Impact of the Human Genome Project,” Battelle
Research Saves Lives

- Deaths from heart disease have decreased 50% over the last 40 years
- Childhood cancer is now a treatable disease, not a death sentence
- A person diagnosed with HIV today can expect to see their 70th birthday
- Between 1995 and 2005, the stroke death rate fell 30 percent

Source: NIH Medical Milestones fact sheet
Return on Investment

• In 1990, an NIH-funded study of osteoporotic fractures helps doctors identify people at high risk for osteoporosis.

• In 2001, the Osteoarthritis Initiative is launched to speed discovery of biological markers for osteoarthritis.

• In 2015, NIH-funded researchers bioengineered a new compound to reduce friction and degeneration in osteoarthritic joints.

Source: NIAMS/NIH
Key Questions

• How much more could NIH contribute to scientific knowledge and finding cures, if resources matched scientific opportunity?
• What can we do in partnership to drive both aspirational and economic messages?
• What should we ask Congress to do?
Current Research!America Advocacy Agenda

- Secure robust increases for NIH, FDA, CDC, AHRQ and NSF in FY17
- Protect health services research (HSR) and social, behavioral, economic (SBE) research from ongoing threats
- Ensure that a House/Senate version of the 21st Century Cures Act, including supplemental funds for NIH and FDA, is signed into law this year
- Work for repeal of the medical device tax
- Build champions for research in Congress
- Build champions for research among candidates for federal office
Environment for Advocacy

- Election year politics
- Heightened public and policymaker demand for transparency and accountability
- Importance of job creation, economic growth and global competitiveness
- Health care issues on front burner, especially cost and access issues
- Scientists are not speaking out
- *Everyone is looking for solutions to what ails us*
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln
Research!America Polling

- Commissioning public opinion polls on research issues for more than 23 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.
Only One Third Say U.S. Will Be a World Leader in Science 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: 29%
- India: 4%
- European Union: 5%
- Brazil: 1%
- Not sure: 26%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in August 2014.
How important do you think it is that the U.S. is a global leader in medical, health and scientific research?

- Very Important: 47%
- Somewhat Important: 33%
- Not Too Important: 6%
- Not At All Important: 3%
- Not Sure: 11%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Opinions Split on Whether Health Care is Based on Latest Research

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

- Yes: 36%
- No: 29%
- Not sure: 33%
- Refused: 2%

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics in August 2012.
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 poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Public Policies Should be Based on Science

Do you agree or disagree with following statement -- Public policies should be based on the best available science.

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Important for Elected Officials to Listen to Scientists

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

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

How trustworthy do you consider each of the following to be as spokespersons for science?

- **Scientists**: 33 Very trustworthy, 48 Somewhat trustworthy, 9 Not very trustworthy, 9 Not at all trustworthy
- **Health care professionals**: 24 Very trustworthy, 52 Somewhat trustworthy, 12 Not very trustworthy, 9 Not at all trustworthy
- **Patient organizations**: 19 Very trustworthy, 47 Somewhat trustworthy, 16 Not very trustworthy, 15 Not at all trustworthy
- **Journalists**: 8 Very trustworthy, 34 Somewhat trustworthy, 32 Not very trustworthy, 16 Not at all trustworthy
- **Bloggers**: 7 Very trustworthy, 21 Somewhat trustworthy, 37 Not very trustworthy, 20 Not at all trustworthy
- **Business leaders**: 7 Very trustworthy, 31 Somewhat trustworthy, 34 Not very trustworthy, 16 Not at all trustworthy
- **Elected officials**: 5 Very trustworthy, 16 Somewhat trustworthy, 34 Not very trustworthy, 33 Not at all trustworthy

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014
And Yet, Despite High Levels of Public Confidence, Scientists are Invisible in Our Society...
Can Americans Name a Living Scientist?
Most Americans Can’t Name a Living Scientist

Please name a living scientist.

- I can
- I cannot

70% I cannot
30% 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%

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?
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.
Do Americans Know Research is Conducted in all 50 states?
Only 1 in 4 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?

- Yes: 26%
- No: 36%
- Not Sure: 39%

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

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
What Can You Do?

• Talk about aspirations for better health, for more research, and talk about return on investment
• 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 the public
THEN...
Rheumatoid arthritis (RA) often shortened lifespan by 10-20 years and there were few effective treatments

NOW...
Thanks to research, we now have several new therapies, including biologics, that target the specific molecules causing painful inflammation

IMAGINE...
Never having to suffer through the pain and disability of RA. Think of the money saved.
In 2015, Americans spent $14.3 billion on Super Bowl-related purchases. That amount is enough to fund NIH research on osteoporosis for more than 95 years!

Sources: National Retail Federation, NIH
In 2015, Americans spent nearly **$19 billion** on Valentine’s Day.

That amount is **25 times more than the combined budgets** for NIH research on multiple sclerosis, muscular dystrophy, chronic pain and arthritis.

Sources: National Retail Federation, NIH
Put a Face on Research: YOURS!
The most important four words a researcher can say and convey are ...
“I work for you.”