World Class Advocacy for World Class Research

Mary Woolley, President, Research!America
WARNING: Failure to be an advocate can be hazardous to your research career
“It's very, very cold out. Very unseasonable... [Climate change] is the greatest hoax ever perpetrated on the American people.”

Sen. James Inhofe (R-OK), Chairman of the Environment and Public Works Committee
“I think NSF should focus more on the pure sciences, on the fundamentals, and be careful to avoid funding research projects that would damage its sterling reputation in the eyes of the public. I’d encourage them to avoid funding studies like shrimps on a treadmill—I hope we never see anything like that again—or alcoholism among prostitutes in Thailand.”

Rep. John Culberson (R-TX-07), member of the House Committee on Appropriations
How important is it that elected officials at all levels listen to advice from scientists?

- **Very Important**: 38%
- **Somewhat Important**: 10%
- **Not Too Important**: 8%
- **Not At All Important**: 2%
- **Not Sure**: 10%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
“Vaccines are very important. Certain ones. The ones that would prevent death or crippling. There are a multitude of vaccines which probably don’t fit in that category, and there should be some discretion in those cases.”  
-- Ben Carson, retired neurosurgeon

“I’m for vaccines, but I’m also for freedom. Even if the science doesn’t say bunching them up is a problem, I ought to be able to spread my vaccines out a little bit, at the very least.”  
-- Rand Paul, Senator (R-KY), ophthalmologist

“Just the other day, 2 years old, 2½ years old, a child, a beautiful child went to have the vaccine, and came back, and a week later got a tremendous fever, got very, very sick, now is autistic.”  
-- Donald Trump
“Wouldn’t it be wonderful if all candidates had science advisers or science advisory committees? They will, if individual scientists step up to the plate.”

The Honorable John Edward Porter, R-IL, former Member of Congress, Research!America chair
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 for more information!
“I Work For You”

Research!America can help you, and everyone in the research community, become an effective advocate for science. We will also continue to be your advocate!
Research!America’s Mission

Making 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.
- Three ‘sister’ organizations in Canada, Australia and Sweden.
Research!America Board Members (partial list)

- The Honorable John Edward Porter, Chair
- The Honorable Michael Castle, Vice Chair
- E. Albert Reece, M.D., Ph.D., MBA, Secretary
- Hortensia Amaro, Ph.D.
- Georges Benjamin, M.D.
- Susan Dentzer
- William Hait, M.D., Ph.D.
- Nancy Brown
- Mary Hendrix, Ph.D.
- Rush Holt, Ph.D.
- Mark McClellan, M.D., Ph.D., MPA
- Harry Johns
- James Madara, M.D.
- The Honorable Kweisi Mfume
- Keith Yamamoto, Ph.D.
- Elias Zerhouni, M.D.
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 & advocate for research

• Ensure that the public hears about research benefits and success stories: Research must not become invisible!
Context for Advocacy

- Questioning of all public expenditures
- Importance of job creation, economic growth and competitiveness
- Election-year politics
- Health care issues are front burner, especially cost and access issues
- Scientists are not speaking out
- Everyone is looking for solutions
- We’re having a “moment” for research
Public Confidence: Steady but Support is Nuanced

Also: 50% of respondents strongly or somewhat agree that scientific research has created as many problems for society as it has solutions.
Confusing Headlines in the Media

Can red wine really stave off Alzheimer’s disease?

Lowering Alcohol Consumption Reduces The Risk of Dementia

A Daily Glass of Red Wine Benefits Your Brain Age
Science in Real Time

- People are understandably confused by the three steps forward/two steps back dynamic process of science.
- By standing back or failing to engage, researchers aren’t helping resolve public confusion.
- Public support for science, and public willingness to engage in research, are at stake.
Current Research!America Advocacy Agenda

- Robust increases for NIH, FDA, CDC and NSF in FY16 & FY17
- Protect AHRQ from proposed termination (House) or 35% cut (Senate)
- Provide input for the Senate Innovation Initiative
  - With the goal of passing legislation that can be conferenced with the 21st Century Cures Act (HR 6)
- End sequestration and prevent other damage to research
- Medical device tax repeal
- Make R&D tax credit permanent
- Build champions for research in Congress
- Build champions for research among candidates for office
Congressional Initiatives on Medical Progress

- **House:**
  - Passed 21st Century Cures Act (HR 6) in July with bipartisan 344-77 vote
  - HR 6 includes five year Innovation Fund with $8.75B for NIH and $550M for FDA as “mandatory” funding
  - Culmination of year-long Energy & Commerce Committee effort to gather stakeholder input

- **Senate:**
  - HELP Committee is gathering stakeholder input and drafting legislation to be released soon; mandatory funding reportedly included
  - Planning mark up of legislation before end of 2015

- **End Goal:**
  - Both chambers reach a conference agreement that is signed into law ASAP
Advocacy at Work: Budget Deal

- Budget deal end of October; action moves to appropriation cmtes
- $80 billion in sequester relief
  - FY16: $25 billion each for defense and nondefense
  - FY17: $15 billion each for defense and nondefense
- Current advocacy opportunity:
  - Maximizing appropriation to research for FY16 and 17 by 12/11/15

Joint Statement by the Aerospace Industries Association, the National Defense Industrial Association, Research!America and United for Medical Research urging Congress to lift discretionary spending caps.
A Challenge: Pass the Starbucks Test
Key Congressional Leaders (1)

SENATE REPUBLICANS

- Majority Leader Mitch McConnell (R-KY)
- Sen. Roy Blunt (R-MS), Chairman Labor-H Appropriations Subcommittee; Commerce, Science, Transportation member
- Sen. Lamar Alexander (R-TN), Chairman HELP Committee; Labor-H Appropriations Subcommittee member

HOUSE REPUBLICANS

- Speaker Paul Ryan (R-WI-01)
- Rep. Hal Rogers (R-KY-05), Chairman Appropriations Committee
- Rep. Tom Cole (R-OK-04), Chairman Labor-H Appropriations Subcommittee
- Rep. Fred Upton (R-MI-06), Chairman Energy & Commerce Committee
- Rep. Kevin Yoder (R-KS-03), Appropriations Committee member
Key Congressional Leaders (2)

SENATE DEMOCRATS

• Democratic Leader Harry Reid (D-NV)
• Sen. Patty Murray (D-WA), Ranking Member HELP Committee and Ranking Member Labor-H Appropriations Subcommittee
• Sen. Dick Durbin (D-IL), Appropriations Committee member

HOUSE DEMOCRATS

• Democratic Leader Nancy Pelosi (D-CA-12)
• Rep. Nita Lowey (D-NY-17), Ranking Member Appropriations Committee
• Rep. Rosa DeLauro (D-CT-03), Ranking Member Labor-H Appropriations Subcommittee
• Rep. Frank Pallone (D-NJ-06), Ranking Member Energy & Commerce Committee
• Rep. Diana DeGette (D-CO-01), Energy & Commerce member
“I don’t think there is any shortage of human talent, but I do think that resources get directed disproportionately in some ways... I think that maintaining a national science base is just as important as maintaining a national industrial base.”

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. That’s something I will be very interested in exploring as part of our bipartisan effort in the coming weeks and months.”

Rep. Patty Murray (D-WA), Ranking Member HELP Committee and Ranking Member Labor-H Appropriations Subcommittee
Porter’s Principles

- Our simple guide for meetings with Members of Congress, as well as advocacy messages for making research to improve health a higher national priority.

http://www.researchamerica.org/advocacy-and-action
“Pick Up the Pen” Moment
Young Scientists as Advocates

- HHMI Fellowship
  - Post-docs with an interest in science policy recruited to work with us
- Campaign for Cures
  - Partnering with post-docs to engage with candidates
- Advocacy Academies
  - Bringing post-docs from across the country to Washington for intensive policy and advocacy training

Pictured above: hard copy of Campaign for Cures toolkit materials sent to post-doc organizations.
“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:
Tell Your Story, Not Your Data!

“I’ll pause for a moment so you can let this information sink in.”
Know Your Audience and Your Audience’s Audience
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln
• 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.
Majority Agree that Basic Research is Necessary

Do you agree or disagree with the following statement? “Even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government.”

- **Strongly agree**: 24%
- **Somewhat agree**: 4%
- **Somewhat disagree**: 11%
- **Strongly disagree**: 4%
- **Not sure**: 15%

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

How important do you think it is that the U.S. is a global leader in medical, health and scientific research?

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

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Many Believe Government Should Prioritize STEM Education, Careers

Do you agree or disagree that the federal government should assign a higher priority to improving education focused on science, technology, engineering and mathematics and careers in those fields?

- Strongly agree: 35%
- Somewhat agree: 15%
- Somewhat disagree: 8%
- Strongly disagree: 4%
- Not sure: 38%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014.
Plurality Willing to Pay More in Taxes to Fund Research

Would you be willing to pay $1 per week more in taxes if you were certain that all of the money would be spent on additional medical research?

- Yes: 44%
- No: 46%
- Not sure: 24%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Scientists Get Too Little Recognition

For each of the following groups do you believe we give too much, too little, or about the right amount of recognition, including salary and awards...

**Entertainment and Sports Figures**
- Too Much: 67%
- Too Little: 7%
- About Right: 17%
- Not Sure: 9%

**People in Business**
- Too Much: 28%
- Too Little: 14%
- About Right: 44%
- Not Sure: 14%

**People in Science and Technology**
- Too Much: 10%
- Too Little: 52%
- About Right: 26%
- Not Sure: 12%

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

- 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.
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?

- Very Important: 51%
- Somewhat Important: 33%
- Not Very Important: 5%
- Not Important At All: 2%
- Not Sure: 10%

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
“Our country needs more scientists who are willing and able to step out in the public arena and to weigh in, clearly and strongly...We need more scientists who can explain what they are doing in language that is compelling and understandable to the public.”

“Scientists should not presume to claim to have better value judgments, to have a better sense of democratic values, than non-scientist citizens. But we can teach the principles, as well as the excitement and the beauty of the science, and we can help them understand the key points that go into making the political, social and value judgments.”

-- “Should scientists play a role in shaping global policy?,” Interview with NPR Science Friday, October 2015.

Rush Holt, Ph.D.
CEO of AAAS and former U.S. Representative (NJ-D)
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
• Support the 21st Century Cures initiative
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
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
In 2014, the National Football League’s revenue was estimated to be $9.5 billion.

That amount is enough to fund NIH sponsored traumatic brain injury research for 68 years!
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!
Why Aren’t More Scientists Engaged in Public Outreach?

- Don’t have time
- Aren’t being asked
- Don’t know how
- “Involvement makes no difference”
- Apathy/don’t want to
- Lack of incentives
- “Non-scientists won’t understand”
- Liability/fear of being misinterpreted
- Happy with the job others are doing

Rank order of responses based on formal and informal polling of scientists
I admire and love my brother [Paul Greengard], but he lives on a higher plane, and what he does is secret, unrevealable. To me, anyway ...

“Every time he took a new job — whether at Albert Einstein College of Medicine or Yale — I’d ask him about it. Then he’d get into electro-physiological properties, and it was all over ...

“Now, he has won the Nobel Prize in physiology or medicine, an honor he shares with two other scientists. In reporting it, the newspapers said their work on the way brain cells communicate might one day help cure diseases like Parkinson’s and Alzheimer’s.

“I’m thrilled he won. Now I know what he does.”

— Chris Chase in a New York Times opinion piece on October 15, 2000
“Everybody in the science and technology community who cares about the future of the world should be tithing 10 percent of his or her time to interacting with the public in the policy process.”

John P. Holdren, PhD
President Obama’s Science Adviser
Put a Face on Research: YOURS!
The most important four words a researcher can say and convey are ...
“I work for you.”
Research!America Works for Researchers

Connect with us

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www.twitter.com/researchamericag
www.youtube.com/researchamericag