World Class Advocacy for World Class Research

Nov. 12, 2015

Janssen Town Hall
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
• Johnson & Johnson was a founding member
Dr. Bill Hait has served on Research!America’s Board of Directors since 2013

Bill has been a speaker at our annual National Health Research Forum. At our 2014 Advocacy Awards Dinner, Dr. Hait presented the Gordon and Llura Gund Award to Kathy Giusti and in 2015 presented this award to Michael Milken.
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 scientists to engage non-scientists & advocate for research
• Ensure that the public hears about research benefits and success stories: Research must not become invisible!
Ensure Policymakers and the Public Understand that Medical Progress is a Team Effort

Government, academia, and the private sector each play essential roles in driving medical progress forward, but too often all the credit is given to one sector and none to the others.
Through Advocacy We Work To...

• Elevate the goal of faster medical progress to a higher priority, worldwide
• Make a compelling case for STEM
• Secure robust funding and 21st Century policies for NIH, FDA, AHRQ, NSF, and CDC
• Advocate a policy environment conducive to rapid private sector innovation: regulatory, tax, intellectual property, health I.T.
• Build champions for research in government
Environment for Advocacy

- Questioning of all public expenditures
- Importance of job creation, economic growth and global competitiveness
- Election politics
- Health care issues on front burner, especially cost and access issues
- Scientists are not speaking out
- Everyone is looking for solutions
- We’re having a “moment” for research in U.S.
Current Congressional Initiatives on Medical Progress

- **House:**
  - Passed 21\textsuperscript{st} 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
Global Impact of Congressional Initiatives

- FDA regulatory changes influence the global conversation about drug and device regulation in other nations
- HR 6 includes sense of congress language that a global pediatric clinical trial network should be established
- HR 6 establishes a non-profit public private partnership that (among other things) is charged with identifying opportunities to work with European and other research and regulatory entities
- International harmonization provisions - could be included in Senate bill or final conference
- NIH conducts research that has global reach, so increase in NIH funding reverberates globally
Advocacy at Work: Budget Deal

- Budget deal reached end of October; action moves to appropriation committees
- $80 billion in sequester relief
  - FY16: $25 billion each for defense and nondefense
  - FY17: $15 billion each for defense and nondefense
- Current advocacy opportunity:
  - Maximize 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.
“We don't have a health care crisis in America, we have a health crisis. And until we deal with the health of Americans and do what we did with polio--when I was a little kid, we eradicated it. You know how much money we spent on polio last year in America? We didn't spend any. We've saved billions of dollars...Focus on the diseases that are costing us the trillions of dollars.”

Mike Huckabee, U.S. presidential candidate, former Governor of Arkansas
Elevate medical progress 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!
Important for Elected Officials to Listen to Scientists

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

- **38%** Very Important
- **42%** Somewhat Important
- **10%** Not Too Important
- **2%** Not At All Important
- **8%** Not Sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
“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, Research!America chair
Communicating with Impact to Non-Scientists

- Briefings on the discovery > development > delivery continuum
- Fact sheets
- Extensive media outreach
- Training/workshops
- Message framing based on evidence
- Public opinion polling

Former CNN White House correspondent Frank Sesno conducts mock interview as part of April 2015 workshop conducted in partnership with George Washington University.
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln
A Finger on the Pulse of Public Opinion

- Research!America has been 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.”

- 24% Strongly agree
- 46% Somewhat agree
- 15% Somewhat disagree
- 4% Strongly disagree
- 11% Not sure

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

- 34% Very Important
- 35% Somewhat Important
- 13% Not Too Important
- 5% Not At All Important
- 13% Not Sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
When it comes to rising health care costs, would you say research to improve health is part of the problem or part of the solution?

- 51% Part of the solution
- 29% Not sure
- 20% Part of the problem

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.
Australians More Likely to Say Research is Part of the Solution

Australians are confident that health and medical research can provide solutions that reduce the cost of health care.

Source: Research Australia public opinion polling, 2015
Australians Value Science

- 93% of Australians say it’s important politicians and public servants listen to advice from scientists
- 90% agree that Australian government should assign a priority to education in science, technology, engineering and math (STEM)
- 91% believe the Australian government should support basic scientific research that advances the frontiers of knowledge even if it brings no immediate benefits
- Only 4% of Australians are unwilling to share health information for research purposes

Source: Research Australia public opinion polling, 2015
### 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)?

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

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, January 2015
Swedes Believe Increased Investment in Medical Research is Valuable

How well do you agree with the following statement?: If Sweden spends more on medical research today, there will be a return in the long term.

Source: Research!Sweden public opinion polling, February 2012
Swedes Consider Pharmaceuticals/Medical Technology Among Most Important Industries

How important do you think it is to put an effort into making Sweden a strong actor in the future, within the following industries?

Source: Research!Sweden public opinion polling, February 2012
Pharmaceutical Industry is Positive Force for Improving Personal Health

On balance, do you feel the pharmaceutical industry is a more positive or more negative force in improving the health of you or your family?

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

Source: Zogby Analytics

Very Positive | Somewhat Positive | Somewhat Negative | Very Negative | Don't Know

2015: 16% Very Positive, 42% Somewhat Positive, 22% Somewhat Negative, 6% Very Negative, 14% Don't Know

2010: 16% Very Positive, 40% Somewhat Positive, 18% Somewhat Negative, 5% Very Negative, 21% Don't Know
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, 0% Not sure
- Health care professionals: 24% Very trustworthy, 52% Somewhat trustworthy, 12% Not very trustworthy, 9% Not at all trustworthy, 0% Not sure
- Patient organizations: 19% Very trustworthy, 47% Somewhat trustworthy, 16% Not very trustworthy, 15% Not at all trustworthy, 0% Not sure
- Journalists: 8% Very trustworthy, 34% Somewhat trustworthy, 32% Not very trustworthy, 16% Not at all trustworthy, 11% Not sure
- Bloggers: 7% Very trustworthy, 21% Somewhat trustworthy, 37% Not very trustworthy, 20% Not at all trustworthy, 15% Not sure
- Business leaders: 7% Very trustworthy, 31% Somewhat trustworthy, 34% Not very trustworthy, 16% Not at all trustworthy, 13% Not sure
- Elected officials: 5% Very trustworthy, 16% Somewhat trustworthy, 34% Not very trustworthy, 33% Not at all trustworthy, 12% Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, January 2014
Despite Relatively 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: 70%
- I cannot: 30%

- 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 (Correct Response) 26%
- No 39%
- Not Sure 36%

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: 2%
- Not Important At All: 5%

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?

• Share your aspirations for better health, for more research and medical progress, and talk about return on investment with non-scientists
• Emphasize how research drives economic activity and creates good jobs
• Convey your personal commitment
• Encourage your colleagues to engage the public
“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

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