Turning a Moment into a Movement: Your Role in Advocacy for Research

Mary Woolley, President and CEO, Research!America
“You can change the image of things to come. But you can’t do it sitting on your hands ... The community should reach out to Congress and build bridges.”

Research!America Chair, Former Congressman John Edward Porter
Advocacy Works!

2015 was a very busy year and we have a lot to celebrate...

- Meaningful increase in FY16 funding for medical research
- Medical Device Tax paused until FY18
- A permanent R&D Tax Credit
- Agency for Healthcare Research and Quality preserved

Now to turn a moment into a movement in 2016!
Current Context for Advocacy

- Questioning of all public expenditures
- Importance of job creation, economic growth and competitiveness
- Election-year politics
- 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
NIH funded HIV/AIDS research:

- 1982: $3.35 million
- 1985: $63.7 million
- 1995: $1.34 billion
- 2000: $2.04 billion
- 2005: $2.95 billion
- 2010: $3.01 billion
- 2015: $3.00 billion
- 2016 (est.): $3.00 billion

Sources: Federation of American Scientists, NIH RePORT
Public Sentiment Won’t be Denied: Breast Cancer

Breast cancer funding at NCI:

- 1990: $81 million
- 2000: $438.7 million
- 2010: $631.2 million
- 2015: $674 million
- 2016 (est.): $699 million

Since 1992, the Department of Defense has provided $3.2 billion in breast cancer research funding

Sources: National Cancer Institute; DoD CDMRP
Nothing About Us Without Us*

*A slogan originating with the South African disability movement in the early 1990’s*
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)

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)

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
How important is it for you to know whether your candidates for Congress believe the government should invest more in medical research?
How important is it for you to know whether your candidates for Congress believe the government should invest more in medical research?

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in June 2016.
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!

Twitter.com/Campaign4Cures
Facebook.com/Campaign4Cures
Research!America recently launched an **online interactive map** of candidates’ views on medical progress where visitors can view hundreds of quotes on issues related to public and private sector research and innovation from candidates who win their state primaries.

The **Campaign for Cures** blog features election news, survey data, commentary and analysis of the presidential race and congressional races in key states on topics relevant to medical progress.
Candidate Views on Research

"And let’s fund the scientific and medical research that spawns innovative companies and creates entire new industries, just as the project to sequence the human genome did in the 1990s”
- Hillary Clinton (July 2015)

“[Alzheimer’s is] a total top priority for me. I have so many friends whose family is devastated by Alzheimer's. So, it’s -- believe me, it’s a total priority...That’s something that we should be working on and we can get an answers. There are some answers. They’ve made less progress than we had hoped as you know. But there’s some answers.”
- Donald Trump (August 2015)
Party Platforms on Research

- DNC platform supports investments in medical research, addressing drug addiction and mental health, investing in AIDS/HIV research and global health issues (Zika, Ebola)
- RNC platform supports partnerships among small businesses and federal research agencies, advancing research and development in health care, reforming FDA and combatting drug abuse
Research!America’s Mission

Making research to improve health a higher national priority

Research!America is an innovator in advocacy for research
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 Board
Members (partial list)

- The Honorable John Edward Porter*, Senior Advisor, Hogan Lovells US LLP
- The Honorable Michael Castle*, Partner, DLA Piper, LLP
- E. Albert Reece, M.D., Ph.D., MBA, Vice President of Medical Affairs; University of Maryland School of Medicine
- Hortensia Amaro, Ph.D., Professor of Social Work and Preventive Medicine, University of Southern California School of Social Work
- Georges Benjamin, M.D., Executive Director, American Public Health Association
- William Hait, M.D., Ph.D., Global Head, Janssen Research & Development
- Nancy Brown, CEO, American Heart Association
- Susan Dentzer, President and Chief Executive Officer, Network for Excellence in Health Innovation
- Martha Hill, Ph.D., RN, Dean Emerita, Professor of Nursing, Medicine & Public Health, The Johns Hopkins University School of Nursing
- The Honorable Rush Holt*, Ph.D., CEO, American Association for the Advancement of Science
- Mark McClellan, M.D., Ph.D., MPA, Director, Center for Health Policy, Duke University
- The Honorable Kweisi Mfume*
- Harry Johns, CEO, Alzheimer’s Association
- James Madara, M.D., CEO, American Medical Association
- Keith Yamamoto, Ph.D., Vice Dean for Research, School of Medicine, University of California, San Francisco
- Elias Zerhouni, M.D., President, Global Research & Development, Sanofi

*Former Member of Congress
Current Hill Advocacy Agenda

- Secure robust increases for NIH, FDA, CDC, AHRQ, and NSF in FY17
- Ensure any continuing resolution (CR) of FY16 funding levels is temporary
- Obtain Senate passage of companion legislation to the House 21st Century Cures Act in September; conference agreement between the House and Senate to be signed into law before the end of 2016
- Protect health services research (HSR) and social, behavioral, economic (SBE) research from ongoing threats of budget cuts
- Build champions for research in Congress
- Push for policy changes and emergency funding that respond to new and emerging health-related challenges (Zika, opioid epidemic, gun violence, etc.)
“...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
- Telephone (random-digit dialing) surveys 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 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.
Health Promotion and Prevention Research Should be a Priority

Compared with other policy areas, how high a priority should Congress make health promotion and disease prevention research?

- 42%: A very high priority
- 36%: A somewhat high priority
- 8%: A somewhat low priority
- 3%: A very low priority
- 11%: Not Sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Majority Willing to Share Personal Health Data for Research

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

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>To advance medical research</td>
<td>59%</td>
</tr>
<tr>
<td>So health care providers can improve patient care</td>
<td>56%</td>
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<tr>
<td>So public health officials can better track diseases and disability and the causes</td>
<td>46%</td>
</tr>
<tr>
<td>None</td>
<td>14%</td>
</tr>
<tr>
<td>Not Sure</td>
<td>12%</td>
</tr>
</tbody>
</table>

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
Most Americans Have Not Participated in Clinical Trials

Have you or anyone in your family ever participated in clinical trials?

- Yes: 7%
- No: 77%
- Not sure: 16%

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?

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

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
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**: 40%
- **Somewhat agree**: 38%
- **Somewhat disagree**: 9%
- **Strongly disagree**: 3%
- **Not sure**: 10%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
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.”

- **43%** Strongly agree
- **34%** Somewhat agree
- **9%** Somewhat disagree
- **5%** Strongly disagree
- **10%** Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in June 2016.
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?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
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, 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 in January 2014
Public Perceptions of Science and Scientists Mostly Favorable

According to the latest National Science Board report:

- Around 40% of Americans express high levels of confidence in the scientific community, second only to the military.
- 70% of Americans say the benefits of science are greater than the harms, and 90% agree that S&T will create more opportunities for future generations.

Source: University of Chicago, National Opinion Research Center, General Social Survey (2006–14)
Cited in: 2016 National Science Board Science and Engineering Indicators
Public Confidence in Institutional Leaders

Around 40% of Americans express high levels of confidence in the scientific community.

Cited in: 2016 National Science Board Science and Engineering Indicators.
And Yet, 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?

I can

17%

- Stephen Hawking (40%)
- Neil deGrasse Tyson (15%)
- Jane Goodall (7%)
- Bill Nye (6%)
- Michio Kaku (4%)
- Richard Dawkins (4%)
- James Watson (2%)
- Ben Carson (2%)
- Other (20%)

I cannot

83%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
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?

- 34% I can
- 66% I cannot

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
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?

- Yes: 28%
- No: 34%
- Not Sure: 37%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2016.
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.
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
- 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
- Take the Campaign for Cures pledge

www.campaignforcures.org

- Month of advocacy encouraging Congress to get the Cures legislation across the finish line when they return to DC in September
- Themed weeks:
  - Discovery (8/1-8/5)
  - Development (8/8-8/12)
  - Delivery (8/15-8/19)
  - Final one-day wrap-up (during 8/22-8/26)
- Get involved at the online advocacy headquarters:
21st Century Cures Legislation

- **House:**
  - Passed 21st Century Cures Act (HR 6) in July 2015 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 passed 19 bipartisan bills including some key provisions of HR 6
  - Chairman Alexander, Ranking Member Murray negotiating final legislative package for Senate consideration
  - Key challenge is to secure “pay-fors” in order to include mandatory funding
Broad Significance of 21st Century Cures Legislation

- Has propelled medical progress into the spotlight.
- Collaborative legislative model that brings patients to the table with policymakers, industry, researchers, and other advocates.
- Demonstrates that better health transcends partisanship, civility is a possibility, and gridlock need not be the rule.
- Connects the dots between discovery, development and delivery - “we are all in this together.”

“Bipartisan passage of the 21st Century Cures Act is a victory for patients and their loved ones – and that ultimately means all of us…We urge the Senate to embrace this opportunity to transform medical innovation, and bring about the kind of progress that helps our nation and its people thrive.”

Statement by Research!America President and CEO Mary Woolley on Passage of 21st Century Cures Act (HR 6) July 10, 2015
Authentic Communication

“While we’re explaining things to somebody, are we ‘reading’ them? Are we relating to them? Are we seeing if they’re getting it...or are we just spraying information at them?”

“If we’re introducing them to [science], then if all we do is turn them away from it, turn them off, then it’s not communication, it’s ex-communication.”

“Pick Up the Pen” Moment
“If you think research is expensive, try disease.”

Mary Lasker, philanthropist and advocate
1900-1994
• Americans spent $3 billion on summer camp for children in 2015.

• That amount is enough to fund NIAMS-sponsored research for nearly 6 years.

Sources: Allianz Global Assistance; National Institutes of Health
Engage Emotion: You Can’t Use Facts To Change Feelings

- Time and again, research has shown that facts and rational analysis do not convince people to change behavior. Behavior change begins when people see something that makes them feel something.
- If you want to change the narrative around a cause, you have to start by changing the way people feel.
Tell your story: Sharon Monsky

“When first diagnosed with scleroderma, Sharon was given less than two years to live. 18 years later, she had beaten the odds in every way and built an organization giving hope to hundreds of thousands of people around the world. Through her pioneering efforts, the SRF has become the nation’s largest nonprofit investor in medical research aimed at understanding scleroderma, discovering improved therapies and, ultimately, a cure.”

-- The Scleroderma Research Foundation

Sharon Monsky received the “Exceptional Contributions as a Volunteer Advocate” Award at Research!America’s first Advocacy Awards Dinner in 1997.
What Else Can You Do?

• Build relationships - patients and researchers join together to meet members of Congress
• Join www.campaignforcures.org
• Don’t sit on your hands during the election - go to town halls, e-mail and call candidates

Image credit: AACR
Put a Face on Research: YOURS!
Research!America Works for You

Connect with us

www.researchamerica.org/blog
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www.youtube.com/researchamerica