Your Role in Advocacy For Global Health Research

Mary Woolley, President and CEO, Research!America

July 19, 2018

NIH Global Health Fellows Program Orientation and Training, Bethesda, MD
Recognizing Dr. Glass’s Leadership

Dr. Roger Glass received the Geoffrey Beene Builders of Science Award for his research and advocacy efforts in global health in the United States and around the world at Research!America’s 2018 Advocacy Award Dinner.
Why Is Your Voice Needed As Well?

• In the U.S. and across the globe, budgets for research are stretched thin
• Global health is not top of mind for most people, including policymakers
• Science does not speak for itself
• Researchers are the most trusted persons to make the case for research
• Many voices = high impact advocacy
We are Proud Advocates for Global Health R&D and Fogarty
Research!America’s Mission

Making research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Research!America: 29 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
- Four ‘sister’ organizations in Canada, Australia, New Zealand and Sweden
“If you think research is expensive, try disease.”

Mary Lasker
1900-1994
“The federal government defending you from Ebola is probably as important as defending you from a terrorist attack because a pandemic will kill more people than a terrorist attack will.”

-- Interview with Bloomberg News, May 19, 2017

Rep. Tom Cole (R-OK-04), Chairman, Labor-H Appropriations Subcommittee
A Nation Worth Defending

- U.S. defense budget for 2018: $654.6B

- Health Security: The National Institutes of Health budget for 2018 is $37.08B

“The NIH... is our nation's Department of Defense for America's personal health”*

Sources: DoD, NIH, Congressman Steve Cohen* (D-TN)
Advocacy vs. Lobbying

To **advocate** means to speak up, to plead the case of another or to champion a general cause.

*It is something that most of us routinely do on behalf of our families, our neighbors, our friends and ourselves.*

**Lobbying**, in general, consists of communications intended to influence specific legislation.

Research!America does both.

*Everyone can be an advocate!*
Advocacy Works!

- Stopped effort to defund the Fogarty International Center in FY18
- Prevented FY18 “rescissions” including proposed $252M cut to USAID Ebola funding
- Doubled the NIH budget in five years, ‘99-‘03
- Secured $2 billion increase for NIH in FY16 and FY17 and $3 billion in FY19
- Achieved increase in FY18 and FY19 discretionary budget caps
- Prevented provisions aimed at stifling fetal tissue and stem cell research
- Prevented taxation of graduate tuition waivers from being included in 2017 tax reform bill
- Secured passage of 21st Century Cures Act including $4.8B innovation fund for NIH
FY19 Appropriations - in the works

- **House FY19 Funding Levels:**
  - NIH - $38.3B ($1.25B increase)
  - Fogarty - $76.64M ($904,000 increase)
  - CDC - $7.6B ($427M increase)
  - BARDA - $587M ($50M increase)
  - USAID - $1.6B ($3.6M increase)

- **Senate FY19 Proposed Funding Levels:**
  - NIH - $39.08B ($2B increase)
  - Fogarty - $78.15M ($3M increase)
  - CDC - $7.87B ($695M increase)
  - BARDA - $562M ($25M increase)
  - USAID - $1.46B ($2.2M increase)

- Timing of final House/Senate bill: Stay Tuned!
Q: What do elected officials and scientists have in common?
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A: Serving the public’s interest.

You can effectively start a conversation with any elected official by thanking them for serving the public’s interest. And then say how you do so!
“...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 26 years:
  - National Surveys
  - State-Based Surveys
  - Issue-Specific Surveys
- 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.
Strong Majority say Americans Should be Concerned about Global Health

When you hear the term global health, do you think it is an issue about which Americans should be concerned?

- Yes: 81%
- No: 9%
- Not sure: 11%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in May 2018.
Concerns with Future Epidemics and Response

Please indicate the extent to which you agree, where '1' means you strongly disagree, and '5' means you strongly agree?

- The global community will experience an epidemic in the next 10 years
  - 17% strongly agree
  - 20% agree
  - 42% neutral
  - 12% disagree
  - 9% strongly disagree

- The global community will experience an epidemic in the next 10 years that includes cases in the U.S.
  - 15% strongly agree
  - 19% agree
  - 42% neutral
  - 16% disagree
  - 8% strongly disagree

- The U.S. is prepared to respond to another epidemic like Ebola
  - 11% strongly agree
  - 23% agree
  - 42% neutral
  - 16% disagree
  - 9% strongly disagree

- The global community is prepared to respond to another epidemic like Ebola
  - 8% strongly agree
  - 20% agree
  - 40% neutral
  - 21% disagree
  - 10% strongly disagree

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2018.
Many Confident That U.S. Government Can Prevent Infectious Disease Outbreak

How confident are you that the federal government can prevent a major infectious disease outbreak in the U.S.?

- Very confident: 14%
- Somewhat confident: 26%
- Not too confident: 10%
- Not at all confident: 3%
- Don't know/Refused: 3%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in May 2018.
Which statement is closest to your view: (A) The federal government should do more to educate the public about global disease outbreaks and the risk to the U.S. (B) The public is sufficiently informed on global health issues and the government should devote its time and resources to other national priorities.

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in May 2018.
Important for Scientists to Engage with Policymakers

How important is it for scientists to inform elected officials about their research and its impact on society?

- Very Important: 49%
- Somewhat Important: 32%
- Not Too Important: 9%
- Not At All Important: 3%
- Not Sure: 7%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
Important for Scientists to Engage with Public

How important is it for scientists to inform the public about their research and its impact on society?

- Very Important: 58%
- Somewhat Important: 28%
- Not Too Important: 6%
- Not At All Important: 2%
- Not Sure: 6%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
Americans Express Confidence in Military, Scientists

% of U.S. adults who say they have ___ of confidence in each of the following groups to act in the best interests of the public

<table>
<thead>
<tr>
<th>Group</th>
<th>A great deal</th>
<th>A fair amount</th>
<th>Not too much</th>
<th>No confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>The military</td>
<td>33</td>
<td>46</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Medical scientists</td>
<td>24</td>
<td>60</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Scientists</td>
<td>21</td>
<td>55</td>
<td>18</td>
<td>4</td>
</tr>
<tr>
<td>K-12 principals and superintendents</td>
<td>13</td>
<td>53</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>Religious leaders</td>
<td>13</td>
<td>39</td>
<td>32</td>
<td>14</td>
</tr>
<tr>
<td>The news media</td>
<td>5</td>
<td>33</td>
<td>40</td>
<td>21</td>
</tr>
<tr>
<td>Business leaders</td>
<td>4</td>
<td>37</td>
<td>44</td>
<td>14</td>
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<tr>
<td>Elected officials</td>
<td>3</td>
<td>24</td>
<td>54</td>
<td>19</td>
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</tbody>
</table>

Note: One third of respondents randomly assigned to rate “medical scientists”; two-thirds randomly assigned to rate “scientists.” Other questions asked of all, N = 4,563. Respondents who did not give an answer are not shown.


PEW RESEARCH CENTER
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?

- Yes, I can name [16%]
- No [84%]

- Stephen Hawking (42%)*
- Neil deGrasse Tyson (27%)
- Bill Nye (6%)
- Jane Goodall (5%)
- Elon Musk (3%)
- Michio Kaku (2%)
- James Watson (2%)
- Richard Dawkins (1%)
- Anthony Fauci (1%)

*deceased

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
Do Americans Know Where Medical or Health 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?

- Yes, I can name: 35%
- No: 66%

- Mayo Clinic (21%)
- Johns Hopkins University (12%)
- St. Jude Children’s Research Hospital (10%)
- NIH (6%)
- Cleveland Clinic (5%)
- American Cancer Society (4%)
- CDC (4%)
- Duke University (2%)

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
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:** 24%
- **No:** 32%
- **Not Sure:** 45%

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
Americans greatly overestimate U.S. foreign aid spending. Americans believe foreign aid absorbs more than 30% of the federal budget. In fact, it accounts for less than 1%. Global health spending makes up about 0.25% of the federal budget, and Fogarty makes up about .006%.

Source: January 2016 Health Tracking Poll, Kaiser Family Foundation
Increase the Visibility of Science
What Can You Do?

- Talk to non-scientists about shared aspirations for better health and strong return on public investment
- Use in-the-moment news to illustrate benefits of research
- Emphasize how research drives economic activity in every state and creates good jobs
- Convey your personal commitment
- Encourage your colleagues to engage the public
Identify a Deep Need

- The first reason we have not been able to engage the audience is simple: we are telling the wrong story.
- We are telling our story, not theirs.
- The first thing you must do is convey that your mission helps to meet their needs.
Aspirational Communications

THEN... 130,000 new cases of HIV infection occurred annually in the U.S. during the peak of the AIDS epidemic in the 1980s, and most cases were fatal.

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

IMAGINE... (thanks to research) A universal HIV vaccine and complete eradication of HIV/AIDS, worldwide.

Research is the solution to what ails us!
Skepticism is Not Just for Scientists

• Thanks to the communication revolution, anyone can witness science in essentially ‘real time’ and can be confused by the three steps forward/two steps back *dynamic process* of science.

• By standing back or failing to engage, scientists aren’t helping resolve public confusion.

• **Healthy skepticism** is a good thing in public discourse, just as it is in science!
Americans spent $5.5 billion on ice cream in 2017.

That amount could fund the NIH Fogarty International Center for almost 76 years!

Sources: Statista, NIH
Re-Cap: How to Think About Talking to Non-Scientists

- Know your audience
- Use the Then-Now-Imagine message frame
- Be in the moment
- Understand and align with public sentiment
- Remember -- if people are skeptical, they are thinking like scientists!
- Convey your personal commitment/passion

**Communicating well demonstrates understanding, sensitivity and accountability.**
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 You

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www.youtube.com/researchamerica