Winning Hearts and Minds for Health and Medical Research

Mary Woolley, President and CEO, Research!America
How to Win Hearts and Minds

- Be visible
- Build relationships
- Share your passion
- Offer evidence
- Make regular engagement and public outreach the new normal

Say and Convey: I serve the public’s interest!
UC San Diego is Winning Hearts and Minds

- Community health screenings
- Summer internships and research opportunities for K-12 and undergraduate students
- Expanding Your Horizons Conference
- Bruce V. Bigelow Memorial Science Communications Fellowship
- Podcast: “N Equals One”
- Community Health Needs Assessments (CHNA)
UCSD Science Policy Fellows Program

- Interdisciplinary training
- Closing the gap between physical and social sciences across campus
- Science students may take classes at GPS; includes science communication curriculum
UCSD SciPAC: 2018 Research!America Microgrant Recipient!

- SciPAC at UC San Diego: Held roundtable event with scientists at UCSD and candidates in the 2018 midterm election
- Hosted a “ballot review party:”
  - Informed graduate students and postdocs about election processes and candidates
  - Summarized the propositions in plain language
- SciPAC merged into Graduate Student Association (GSA); students can contact GSA to plan events or find other like-minded students
Research!America’s Mission

The Research!America alliance advocates for science, discovery, and innovation to achieve better health for all.

*Research!America is an innovator in advocacy for research*
Research!America: 30 Years of Putting Research on the Public Agenda

- Nonprofit alliance with member organizations drawn from academia, independent research institutes, industry, patient organizations and scientific societies
- 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
30 Years of Putting Research on the Public Agenda: Highlights

- 1989: Research!America Founded
- 1993: NIH Budget Doubled
- 2005: Public Health Thank You Day Launched
- 2006: Public Health Thank You Day Launched
- 2007: Public Health Thank You Day Launched
- 2012: NIH receives $2 billion increase
- 2016: NIH receives $5 billion increase
- 2017-2019: NIH receives $5 billion increase
- 2018: NIH receives $5 billion increase
- 2019: NIH receives $5 billion increase

SaveResearch.org
Advocacy Works!

- Doubled the NIH budget in five years, 1999-2003
- Included $10 billion for NIH and $3 billion for NSF in “ARRA” (economic stimulus) funding 2009-2010
- Secured $2 billion increase for NIH in FY16, FY17, and FY19 and $3 billion increase for NIH in FY18
- Secured passage of 21st Century Cures Act including $4.8 billion innovation fund for NIH in 2016
- Prevented one-size-fits-all cap on “indirect cost” reimbursement in 2017
- Prevented taxation of graduate tuition waivers from being included in 2017 tax reform bill
- Raised “sequestration” budget caps in 2013, 2015, 2018 and now in 2019!
## Advocacy State of Play - Funding

<table>
<thead>
<tr>
<th>Agency</th>
<th>FY19 Enacted</th>
<th>Research!America's FY20 Asks</th>
<th>House Appropriations Subcommittee Drafts</th>
<th>Senate Appropriations Drafts</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH</td>
<td>$39.08</td>
<td>$41.60</td>
<td>$41.10</td>
<td>$42.08</td>
</tr>
<tr>
<td>CDC</td>
<td>$7.280</td>
<td>$8.30</td>
<td>$8.30</td>
<td>$7.463</td>
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<tr>
<td>FDA</td>
<td>$3.080</td>
<td>$3.49</td>
<td>$3.26</td>
<td>$3.148</td>
</tr>
<tr>
<td>NSF</td>
<td>$8.10</td>
<td>$9.00</td>
<td>$8.64</td>
<td>$8.317</td>
</tr>
<tr>
<td>AHRQ</td>
<td>$0.34</td>
<td>$0.46</td>
<td>$0.36</td>
<td>$0.256</td>
</tr>
</tbody>
</table>

### Action Needed!
Congress has passed a Continuing Resolution (CR) that expires midnight November 21, 2019. CRs provide temporary funding but discourage scientists and stall long-term projects.

*Billions*
National Institutes of Health Appropriations
Fiscal Year 1989 – 2020

Appropriations (billions)


Appropriations (current dollars) with Supplemental Appropriation ARRA CPI adjusted (1989 dollars)

Proposed FY20 Budget
Senate: $42.08 billion
House: $41.10 billion

CR Funding Level:
$39.08 billion

No Budget Deal:
$35.18 billion

CPI Adjusted FY20 Budget
Senate: $20.51 billion
House: $20.03 billion

CPI Adjusted CR Funding Level:
$19.05 billion

CPI Adjusted No Budget Deal:
$17.14 billion
Advocacy State of Play - Policy

• Work to minimize negative impact of fetal tissue research policy changes.
• Help secure reauthorization of the Patient-Centered Outcomes Research Institute (PCORI).
• Make case for measured approach to issue of “undue foreign influence.”
• Promote policy environment in which both public sector and private sector-driven R&D thrive, and that encourages cross-sector collaboration.
“You can change the image of things to come. But you can’t do it sitting on your hands...The science community should reach out to Congress and build bridges.”

Research!America Chair Emeritus, Former Congressman John Edward Porter
How important is it for scientists to inform elected officials about their research and its impact on society?

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

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

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

Source: A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2018.
A Challenge: Pass the Starbucks Test
Some of the people who represent you

Senator Dianne Feinstein (D-CA)
Senate Judiciary Committee (Ranking Member)
Senate Appropriations Committee

Rep. Scott Peters (D-CA-52)
House Committee on Energy & Commerce

Senator Kamala Harris (D-CA)
Senate Homeland Security Committee
Senate Budget Committee

Live and/or vote off-campus or outside La Jolla?

Visit House.gov to find your Representative!
## Are Your Representatives Members of the NIH Caucus?

<table>
<thead>
<tr>
<th>Member</th>
<th>NIH Caucus?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sen. Dianne Feinstein</td>
<td>Yes</td>
</tr>
<tr>
<td>Sen. Kamala Harris</td>
<td>No</td>
</tr>
<tr>
<td>Rep. Scott Peters</td>
<td>No</td>
</tr>
</tbody>
</table>
Q: What do elected officials and scientists have in common?
Q: What do elected officials and scientists have in common?

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 serve the public’s interest.
Make Advocacy Opportunities

Be ready with your “ask”

Now:

• Make the case for reaching a final agreement on funding levels - no more continuing resolutions!

Tweet now: Patients need progress now. Complete the FY20 budget. #CRsStopProgress

Evergreen:

• Ask your representatives to join the NIH Caucus

Take Every Opportunity to Say “Thank You”
Constituent voices matter

When congressional staff were asked what advocacy factors would have some or a lot of influence:

- 94% said “in-person issue visits from constituents”
- 92% said “individualized email messages” from constituents

Constituent interests matter

- 91% of congressional staff said it’s helpful to have information about the impact the bill/issue would have on the district or state.
- 79% percent said a personal story from a constituent related to the bill or issue would be helpful.

➢ Research!America can help you frame your story!

Another thing elected officials and scientists have in common?

They love to look at data!
“...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% to +/-2.1%. The data are weighted in two stages to ensure accurate representation of the U.S. adult population.
Rising Health Care Costs Are Top Health Concern

What is the single most important health issue facing America? (Choose one)

<table>
<thead>
<tr>
<th>Health Issue</th>
<th>2019</th>
<th>1992</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rising Health Care Costs</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Substance Abuse/Opioid Abuse/Drug Abuse</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>Gun Violence</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Obesity</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Other (Specify)</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Suicide</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>1%</td>
<td></td>
</tr>
</tbody>
</table>

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
Two Thirds Concerned Life Expectancy Will Continue to Decline

For the third year in a row, the average life expectancy in the U.S. has declined. The average life expectancy is now 78. The average life expectancy in other industrialized nations is higher. How concerned are you that life expectancy in the U.S. will continue to decline?

- Very concerned: 31%
- Somewhat concerned: 36%
- Not too concerned: 19%
- Not at all concerned: 5%
- Not sure: 9%

6% increase in total concerned – up to 67%, from 61% in 2018

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
Many Unsure Which Nation Will Be the World Leader in Health Care in 2050

In your view, which of the following nations will be considered the number one world leader in health care in the year 2050? (Choose one)

NOT SURE 27%
UNITED STATES 27%
CANADA 16%
JAPAN 7%
CHINA 6%
OTHER 5%
GERMANY 5%
UNITED KINGDOM 4%
FRANCE 2%
SOUTH KOREA 0.1%
RUSSIA 0.0%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
U.S. Global Standing in Science and Innovation in 2050: Public Confidence Not Strong

Which statement comes closer to your views?

**Statement A:** America’s global preeminence in science and innovation will strengthen by the year 2050.

**Statement B:** America’s global preeminence in science and innovation will weaken by the year 2050

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
Increasing Support for Research into Health Disparities

Studies show that certain health problems such as cancer, 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 2019

Those who say “important” has increased 2 years in a row. Up from 73% in 2017 to 82% now.
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.

* Notable increase in agreement since 2017

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
Majority Agree Discussion of Clinical Trials Should be Part of Standard Care

Do you agree or disagree that health care professionals should discuss clinical trials with patients diagnosed with a disease as part of their standard of care?

![Pie chart showing the percentage of responses to the question.]

- **47%** Strongly agree
- **39%** Somewhat agree
- **9%** Somewhat disagree
- **4%** Strongly disagree
- **5%** Not sure

What do researchers think?

- Percentage of researchers concerned about lack of scientific appreciation and literacy among the general public has increased - 38% in 2003, now 49% in 2019

- Welcome news: More than 70% of researchers say they’ve been involved in some form of outreach during the past 12 months

Source: Sigma Xi, The Scientific Research Honor Society and Research!America, 2019
What do researchers think?

- 82% think misinterpretation of research by media, policy, or public discussion is a large or medium problem in public confidence in research (the problem is with other people)

- 70% think that explaining research to the public in plain English would help people judge research more effectively (there’s a role for researchers here!)

“Trust in Research,” Elsevier Customer Insights, June 2019
Americans Express Confidence in Military, Scientists

Americans’ trust in military, scientists relatively high; fewer trust media, business leaders, elected officials

% 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

- The military: Great deal 39, Fair amount 41, Not too much 15, None at all 4
- Scientists: Great deal 27, Fair amount 52, Not too much 17, None at all 5
- Religious leaders: Great deal 9, Fair amount 40, Not too much 34, None at all 16
- The news media: Great deal 8, Fair amount 32, Not too much 35, None at all 25
- Business leaders: Great deal 5, Fair amount 40, Not too much 42, None at all 13
- Elected officials: Great deal 3, Fair amount 22, Not too much 52, None at all 23

Note: respondents who did not give an answer are not shown. Source: Survey conducted Jan. 29 - Feb. 13, 2018 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? (participants could list more than one; open-ended)

- Yes, I can name
- No/Not Sure

80% 20%

- Neil deGrasse Tyson (23%)
- Bill Nye (8%)
- James Watson (7%)
- Jane Goodall (6%)
- Stephen Hawking* (3%)
- Alan Guth (3%)
- Michio Kaku (3%)
- Richard Dawkins (3%)
- Tim Berners-Lee (3%)
- Elon Musk (2%)
- Noam Chomsky (2%)
- Other (39%)

* deceased

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019
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? (participants could list more than one; open-ended)

- Yes
- No/Not Sure

35% Yes
66% No/Not Sure

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%)
Other (40%)

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 in All 50 States

To the best of your knowledge, would you say that medical research in the U.S. is conducted in all 50 states?

- Yes: 27%
- No: 32%
- Not sure: 41%
Increase the Visibility of Science
Next week: Nobel Announcements

- UCSD: 16 previous Nobel recipients!
- Opportunity to tell stories of perseverance and discovery
  - Celebrate the winners!
  - Visibility is part of public support!
“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
Tell the right story

- 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.
“I was frankly useless at interviews, particularly live TV... I was a typical academic, accustomed to stating the problem, discussing what methods you use to examine it and what the conclusions might be. By the time I reached my main message, most had switched to another channel.”
Changing the narrative

Lead with “why”
Don’t talk first about “what” you do or “how” you do it.
We need more drugs to treat childhood brain cancers

Name your adversary
What does your audience fear? What are you doing to defeat it?
A mysterious vaping-related illness has killed 12 people

Tell a tale of adventure
Exploration, adventure, urgency makes a good story
Nanomedicine is pushing the frontiers of how disease is studied and treated
Skepticism is Not Just for Scientists

- People are understandably confused by the three steps forward/two steps back *dynamic process* of science.
- By standing back or failing to engage, researchers and advocates aren’t helping resolve public confusion.
- The public remains positive in the kinds of questions they are asking about science.
- **Healthy skepticism** is a good thing in science and in public discourse!
Be visible

Jennifer Doudna, PhD, holding a model of the CRISPR-Cas9 protein (Photo: UC Berkeley)

Breakthrough documentary about Jim Allison debuts worldwide this month!
You serve the public interest

• Talk about who you are (and who “we” scientists are).
  • We are the kind of people who cure cancer.
  • We are the kind of people who go to the moon.
  • We are the kind of people who go into the unknown.
  • We are the kind of people who protect Americans from threats.

• Speaking to who you are helps people connect to you and your story.
Advocacy Action From Your Desk

- Email, tweet or call your member of Congress
- Stay informed - read our Weekly Letter
- Invite Research!America to host an online or in-person advocacy training

Visit http://bit.ly/RACRs19 to take action: Tell Congress to complete FY20 appropriations!

Einstein’s desk. Source: Defining Creativity
Advocacy Action in Your Community

• Attend and support university “nerd night” or “science on tap” events

• Support colleagues who get involved with the community
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) eradicating HIV completely.

Research is the solution to what ails us!
Relatable Communications
AKA Social Math


- That amount could fund the National Institute for Mental Health for over 6 years!

Sources: National Research Federation, NIH
Re-Cap: How to Think About Talking to Non-Scientists

- Know your audience
- Use the Then-Now-Imagine message frame
- Be visible
- Use emotion
- 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 scientist can say and convey are ...
“I work for you.”
Research!America Works for You

Connect with us

www.researchamerica.org/blog
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www.twitter.com/researchamerica
www.youtube.com/researchamerica
www.instagram.com/research_america/