Advocacy and Public Policy

Mary Woolley, President, Research!America
“Every public health decision is made on a political decision.”

William Foege, MD, MPH
Senior Fellow, Bill & Melinda Gates Foundation; Former Director, CDC
A Shout-Out!

- Co-author of Mental Health Parity Act of 1996
- Conceptualized and launched the One Mind for Research Campaign
- Honored by Society for Neuroscience, American Psychiatric Association and others
- Member of Congress, 1995-2011
Research!America: 23 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
- Research!America is a proud partner of the One Mind for Research Campaign
Our Key Objectives

- Increase investment in domestic health-related R&D
- Increase investment in global health-related R&D
- Ensure that R&D investments reach patients by improving the policy environment
- Promote science overall and counter attacks made on science
Select Research!America

Accomplishments:

• Leadership in doubling the National Institutes of Health budget (1999-2003)
• Leadership in advocacy for 2009 ARRA (stimulus) funding for federal research agencies
• Leadership in advocacy for FY12 NIH budget increase
• Ongoing leadership in:
  • public opinion polling on medical and health research
  • message development for research advocacy
  • media attention to research
What We Faced in 1989:

“Preoccupation by Congress and the Administration with deficit reduction and competition for appropriations in a resource-scarce environment have resulted in woeful under funding of government agencies involved in medical research”

– from Research!America’s Charter
What Can We Learn from 1995?

- The initial draft of the congressional budget included a 5% cut in NIH funding for five straight years—25% total
- John Edward Porter, then-Chairman of the House Appropriations LHHS Subcommittee and a hand-picked group of business leaders and Nobel laureates convinced Speaker Gingrich to reverse course
- Patient advocates and scientists spoke out to make the case for research
- NIH was protected from cuts and later, its budget was doubled

Similar:
- Recession economy
- Change of party in House from previous election

Different:
- No true champion in Congress
- Broader range of beliefs in House majority

Always:
- Decisions will be made based on priorities and monies will be appropriated
- Advocates will be heard if their voices are unified and persistent!
When Priorities Shift: Post 9/11

• Office of Homeland Security created Sept. 22, 2001
• In 2001, the federal government spent $20.7 billion on homeland security
• By 2003, it spent $42.5 billion; in 2012, it was expected to spend $60.5 billion

Photo by Thomas E. Franklin, *The (Hackensack, NJ) Record*

Sources: Dept. of Homeland Security; Congressional Budget Office
## Some Federal Funding Comparisons

<table>
<thead>
<tr>
<th>Agency</th>
<th>President’s request (FY13)</th>
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<tbody>
<tr>
<td>Dept. of Defense</td>
<td>$613.9 billion</td>
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<tr>
<td>Dept. of Education</td>
<td>$69.9 billion</td>
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<td>NIH</td>
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<td>NASA</td>
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<td>Dept. of Transportation</td>
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<td>FDA</td>
<td>$2.5 billion</td>
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Sources: WhiteHouse.gov
When Public Voices Won’t be Denied: HIV/AIDS

- Federally funded AIDS research:
  - 1990: $740.5 million
  - 2011: $3.06 billion
  - 2012 (est.): $3.08 billion

Sources: National Academies, NIH RePORT
When Public Voices Won’t be Denied: Breast Cancer

Breast cancer funding at NCI
- FY90: $81M; FY00: $438.7M; FY10: $631.2M

Since 1992, the Department of Defense has funded more than $2.8 billion in breast cancer research

Sources: Oncology Times; National Cancer Institute; DoD CDMRP
When Public Voices Won’t be Denied: Alzheimer’s

The cost of Alzheimer’s:

- If nothing is done, treating Alzheimer’s in the U.S. will cost $1.1 trillion in 2050 (in today’s dollars)

National Alzheimer’s Project Act:

- Adds $156M to tackle Alzheimer’s in next two years
- $130M dedicated to research, a 25% increase

Sources: NIH RePORT (Categorical Spending), WhiteHouse.gov
Public Support Matters

“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln
Research!America Poll Data

- Commissioning public opinion polls on research issues for 20 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.
Americans: U.S. Losing Its Competitive Edge in Innovation

Do you agree or disagree with the following statement? “The U.S. is losing its global competitive edge in science, technology and innovation.”

- 29% Strongly agree
- 13% Somewhat agree
- 6% Somewhat disagree
- 4% Strongly disagree
- 4% Not sure

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
China, On the Rise

“U.S. R&D expenditures accounted for about 31% of the worldwide total, down from 38% a decade earlier. The combined R&D expenditures of 10 Asian economies [including China and Japan] rose steadily to reach U.S. levels in 2009, driven mostly by China, now the second largest R&D performing nation.”

Source: National Science Board, Science and Engineering Indicators 2012
Research is Part of the Solution to Rising Health Care Costs

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?

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
Then, Now, Imagine: Heart Disease

THEN...
heart disease killed quickly and without warning

NOW...
over the past 35 years, U.S. age-adjusted mortality from cardiovascular disease declined 50%

IMAGINE...
eliminating preventable deaths due to heart disease

Source: Health Affairs (2007)
Opinions on America’s Most Important Health Issue

What would you say is the single most important health issue facing people in the U.S. today? (first volunteered responses)

Source: Public Opinion Polls, 1992-2010
Physical and Mental Health Not Treated with Equal Importance

Do you think that mental health or physical health are treated with equal importance in our current health care system?

- Treated with equal importance: 24%
- Physical health treated with more importance: 66%
- Mental health treated with more importance: 4%
- Don't know: 6%

Americans: More Investment Needed for Military Veterans

Would you say government investment in health research for the benefit of military veterans and service members is ...

- 33% About right
- 48% Not enough
- 14% Not enough
- 5% Too much

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
Most Don’t Know Their Elected Officials’ Positions on Research

How well informed would you say you are about the positions of your senators and representative when it comes to their support of medical, health and scientific research?

- Very well informed: 7%
- Somewhat well informed: 8%
- Somewhat uninformed: 25%
- Very uninformed: 24%
- Not sure: 36%

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
A Challenge: Pass the Starbucks Test
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
Advocacy in Action: Kerri Mowen, PhD

- Assistant professor, Dept. of Chemical Physiology, The Scripps Research Institute, La Jolla, CA
- Worried about cuts in NIH funding, she created an online petition; 4,000 people signed on
- That led to a front-page story in the San Diego Union-Tribune, calling more attention to the issue
Advocacy in Action: Emily Norton

“Medical research is a critical issue for New Hampshire, for the country and for our health. Unfortunately, our elected representatives and the presidential candidates have not been talking about medical research. We need to work together to make sure policymakers recognize just how important medical research is for our nation's health and our future.”

—Emily Norton, former Research!America intern
Your Candidates-Your Health for the 2012 Elections

- Outreach to candidates
  Candidates for federal office will be invited to participate by providing responses to a questionnaire about health, research and related issues

- Extensive public outreach through the Research!America advocacy network and sponsoring partners to encourage candidates for federal office to share their views

www.yourcandidatesyourhealth.org

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