World Class Advocacy for World Class Research

Mary Woolley, President, Research!America

June 25, 2012
Career Commitment to Advocacy for the NIH

- 1972: Joined then-largest NIH-funded clinical trial
- Later became CEO of Medical Research Institute of San Francisco
- President and CEO of Research!America since 1990
The NIH in 1972

- Total NIH funding: $1.506 billion
- In 1972, NIH consisted of 15 institutes and centers; today there are 27
- Current institutes and centers that didn’t exist in 1972:

Sources: NIH Almanac
Return on Investment

• Deaths from heart disease have dropped 60% in the past 40 years; the cost to each American: $3.70 per year

• In 2011, NIH spending produced more than $62 billion in economic activity

Source: USA Today interview with Francis Collins in August 2011; “NIH’s Role in Sustaining the U.S. Economy,” United for Medical Research.
Return on Investment

• Initial $4 billion HGP investment led to economic impact of $796 billion, created 310,000 jobs

• The resulting industry generated $6 billion in federal, state and local taxes in 2010

Sources: “Economic Impact of the Human Genome Project,” Battelle
Key Questions

• How much more could NHGRI/NIH contribute with funding that aligns with current scientific opportunity?
• How can we all drive that aspirational message while also making the case for return on investment to date?
Yes, NIH has a large budget. But compared to what?
You’ve Gotta Be Kidding?!

- U.S. amusement parks and attractions earned $11 billion in revenue in 2011.
- That sum would fund the National Human Genome Research Institute for more than 21 years!

As of late May, Apple’s market capitalization stood at $526 billion.

That sum would fund the National Institutes of Health for more than 17 years!

Sources: Seeking Alpha; NIH FY2012
Realities of Current Environment

- Overriding public concern re: job creation and economic growth
- Hostility to federal funding; anger at public employees
- Threat of sequestration/fiscal cliff
- Health care conversation will heat up after Supreme Court ACA ruling
- Election-year politics: Role of government
Sequestration: Health Research at the Breaking Point

- Research!America report illustrates the devastating effect if sequestration, or 7.8% across-the-board cuts, goes into effect.
- NIH would lose $2.39 billion, or the equivalent of more than 4.5 times the NHGRI budget in FY12.

Source: NIH Almanac
“This is the most important election of my lifetime.”

Research!America Chair, NIH Champion, Former Congressman John Edward Porter
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’s Mission

Making research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Research!America Goals

- Ensure that the public hears about research and its benefits
- Achieve more funding for medical and health research
- Advocate a policy climate that stimulates rather than impedes research and development
- Empower others to advocate for medical and health research
Current Research!America Emphases

- Leading the community in framing the case for research, esp. the economic case
- Building champions
- Avoiding sequestration and other damage to research
- Making research for health part of the election-year conversation
- Assuring accountability to taxpayer
How to Think About Communication

• Know your audience

• Be in the moment

• Be prepared to address public concerns

• Align with public sentiment

• Convey personal commitment/passion

• Remember the most important four words
### The Language of Science is Jargon to Non-Scientists

<table>
<thead>
<tr>
<th>Scientific Term</th>
<th>Non-Scientific Term</th>
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<td>Proteomics</td>
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<td>Clinical research</td>
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<td>Translational research</td>
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<td>Protocol</td>
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<td>Pandemic, epidemic</td>
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<tr>
<td>Indices</td>
<td>Placebo-controlled</td>
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*Avoid all acronyms!*
Economic Impact Messages

- Research drives innovation and productivity
- Research creates jobs
- Research fuels local & regional economies
- Research helps control health care costs
- Research can contribute to growth and savings in all types of businesses
Research Creates Good Jobs

- In 2011, the National Institutes of Health created and sustained 432,000 jobs.
- The average wage in the U.S. is $45,230.
- The average wage for a life science worker in the U.S. is $65,470.

Research Drives the Economy

Investment in research saves lives and money

**Fact about: Research: An Economic Driver**

**Why invest?**
- Our nation's most valuable asset is human capital.
- Health! Americans are well to reduce economic growth, promote productivity and global competitiveness.
- Research provides high-calibre high-wage jobs for Americans. The U.S. needs them now to train the next generation of scientists.
- Innovation is key to global competitiveness, new and better jobs, increased economic growth and the improvement of overall wellbeing.
- Chronic diseases such as heart disease, cancer, diabetes and asthma cost the U.S. $1.7 trillion a year.
- Personalized medicine offers the prospect of reducing costs and improving patient outcomes by using diagnostic tools to reach patients to treatments and preventive medications.

**Saving Lives Means Saving Money**

- U.S. health care system spends $10 billion more in treatment costs for diabetes.
- A breast cancer diagnosis costs $80,000 for 5 years following a diagnosis.
- The U.S. health care system spends $46 billion on treatment costs for heart disease.
- The U.S. health care system spends $95 billion on treatment costs for cancer.

The U.S. investment in research through the NIH has provided an estimated $50,000 return on the economy by improving Americans' health.

**Hope for the Future:**
Our ability to lead in 2020 will be a function of current decisions. Investing in research is a wise and responsible national security policy. We need to ensure that our health care systems remain vibrant, our workforce is trained for the future, and our economy is strong.

“Science is more essential for our prosperity, our security, our health, our environment, and our quality of life than it has ever been before.”

PRESIDENT BARACK OBAMA

“Innovation is the source of U.S. economic leadership and the foundation for our competitiveness in the global economy.”

BILL GATES, CHAIR MICROSOFT CORPORATION
Research Saves Lives

The National Institutes of Health: Working with Academia and the Private Sector to Save Lives

The taxpayer-supported NIH provides funds to hospitals, universities, small businesses, independent research institutions and government labs that strive to understand the biology and risk factors of disease. Companies leverage NIH-funded research and technology into new therapies. Together they develop innovative, life-saving treatments, cures and prevention strategies.

The Impact of Research

- Deaths from heart disease have decreased 50% over the last 40 years
- Childhood cancer is now a treatable disease, not a death sentence
- A person diagnosed with HIV today can expect to see their 70th birthday
- Between 1995 and 2005, the stroke death rate fell 30 percent
- New imaging technologies allow for earlier Alzheimer’s disease diagnosis and treatment
- Vaccines prevent hospitalizations from the flu and dangerous flu-related infections
- New technology allows remote tracking of food borne and contagious illness
- 12 million cancer patients are alive today because of advancements in medicine and science

A Typical Drug Discovery Pipeline

Zellorof: Personalized Medicine Delivers on Cancer

In 2002, NIH-funded researchers contributed to the identification of a protein mutation present in over 60% of melanoma skin cancers. In 2009, Zellorof biotech started Zellorof to treat cancers that have the mutated protein. Before treatment, patients are diagnosed with a first-of-its-kind test to verify that they will respond to Zellorof. Zellorof reduces the risk of death by 63% and has a median survival time of 3 times longer than untreated cancer.

Table

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Examples of Landmark Research Supported by the NIH

The Framingham Heart Study, 1948-on going

- In 1948, citizens of Framingham, MA joined an NIH-funded study to identify causes of cardiovascular disease (CVD)
- Linked smoking, hypertension, high cholesterol, and obesity with CVD
- These findings led to pharmaceutical industry development of therapies to manage hypertension and high cholesterol to prevent heart attacks
- From 1996-2005 hospitalizations from heart attacks decreased 25%
- New enrollment of participants, this study is still identifying new risk factors that contribute to heart disease

Diabetes Prevention Program (DPP), 1998-2010

- The NIH-sponsored DPP evaluated two different ways (medication or weight loss) to reduce the risk of Type 2 Diabetes
- Participants who took a medication to control blood sugars reduced their risk by 31%
- Participants who restricted calories and increased exercise reduced their disease risk by 58%
- Participants who added lifestyle changes saw a 70% reduction in risk
- Ten years later, lifestyle changes and medication still show a significant decrease in diabetes risk
- Shows that it is possible to delay or prevent the onset of diabetes through low-cost lifestyle changes

Gleevec: Pioneering a New Method of Drug Design

- 40 years of research, supported in part by the NIH, culminated in the identification of an aberrant protein that causes Chronic Myelogenous Leukemia (CML), a type of cancer that affects blood cells
- In 2003 the FDA approved Gleevec, an inhibitor designed to precisely target the aberrant protein, developed by a collaboration between Oregon Health and Science University and Novartis
- Before Gleevec, the 5-year survival rate for patients with CML was 27%. Now the 5-year survival rate is over 95%.
- Old cancer therapies were extremely toxic due to lack of tissue specificity. Gleevec showed that it was possible to specifically target tumor tissue and reduce toxicity

AZT: Tackling the HIV/AIDS Epidemic

- In the 1980s, NIH-funded researchers developed AZT (zidovudine) as a cancer therapy, but it was ultimately unsuccessful
- In the 1980s, researchers at NIH and Burnouf-Wellcome found that AZT is an effective treatment against HIV, the virus that causes AIDS
- A person diagnosed with HIV today can live up to 30 more years; triple the life span in the 1980s

1101 King Street, Suite 520
Alexandria, VA 22314
703 730 2577
info@researchamerica.org
Media Fuels Confusion About Science

Kaiser Permanente
October 27, 2011

For Diabetes Patients, Risk of Heart Attack and Stroke Falls as HDL Cholesterol Levels Rise

The New York Times
May 16, 2012

Doubt Cast on the ‘Good’ in ‘Good Cholesterol’

CBS News
May 17, 2012

Two cups of coffee a day cuts risk of dying by 10 percent, research shows

(CBS/AP) How good is coffee for your health? For years, research has gone both ways, with some studies finding it boosts risk for heart disease, while other studies find it could be protective against breast and skin cancers.
Frustration over Conflicting Reports

“I have lost all confidence in any studies dealing with female hormone replacement. I can’t imagine any circumstances that would convince me to follow any course but nature’s.”

— Commenter on The New York Times’ Well blog, April 5, 2011
Science in Real Time

- People are understandably confused by the three steps forward/two steps back *dynamic process* of science.
- By standing back or failing to engage, researchers aren’t helping resolve public confusion.
- Public support for science, and public willingness to engage in research, are at risk if researchers fail to engage.
“...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 more than 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.
Wide Benefits of Research are Convincing Argument for Americans

Do you find the following statement convincing? “Unlike a lot of federal programs, medical and health research produces concrete results that benefit everyone.”

Source: Your Candidates-Your Health Public Opinion Poll, October 2011, JZ Analytics for Research!America
Most 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.”

Source: Your Candidates-Your Health Public Opinion Poll, October 2011, JZ Analytics for Research!America
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?

54% Part of the solution
24% Part of the problem
22% Not sure

Source: Your Candidates-Your Health Public Opinion Poll, October 2011, JZ Analytics for Research!America
Over Half Skeptical that U.S. Will Be a Leader in Health Care

In your view, which of the following will be considered the No. 1 world leader in health care in the year 2020?

- 47% United States
- 28% China
- 18% India
- 2% European Union
- 2% Brazil
- 2% Not sure

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics in March 2012.
Over Half Doubt U.S. Leadership in Science and Technology in 2020

In your view, which of the following will be considered the No. 1 world leader in science and technology in the year 2020?

- United States: 42%
- China: 26%
- India: 7%
- European Union: 2%
- Brazil: 0%
- Not sure: 23%

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics in March 2012.
Despite Skepticism, Americans Aspire to World Leadership

... If current trends continue, other nations will soon match U.S. investment in research and development. In your opinion, how important is it for the United States to maintain its world leadership role?

- Very important: 64%
- Somewhat important: 27%
- Somewhat unimportant: 4%
- Very unimportant: 2%
- Not sure: 3%

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics in March 2012.
Wide Majority Concerned About Effects of Stagnant Funding

Flat and decreasing federal investment in research creates an uncertain future for scientists ... In your judgment, what level of concern is this to the United States?

- 43%: A great concern
- 42%: Somewhat of a concern
- 6%: Not much of a concern
- 7%: No concern
- 2%: Not sure

Source: A Research!America poll conducted in partnership with JZ Analytics in March 2012.
Public Perceptions of Science and Scientists

Science’s impact on society is:

- Mostly positive: 84%
- Mostly negative: 6%
- Other/don’t know: 10%

Professions contributing “a lot to society’s well-being”:

- Members of military: 84%
- Teachers: 77%
- Scientists: 70%
- Medical doctors: 69%

Pew Research Center for the People & the Press, July 2009
And Yet, Despite 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

Can you name a living scientist? (first volunteered responses)

- Yes: 34%
- No: 66%

- Stephen Hawking: 15%
- James Watson: 1%
- Jane Goodall: 1%
- Bill Nye: 1%
- Michio Kaku: 1%
- Neil Degrasse Tyson: 1%
- Other: 14%

Source: Your Congress - Your Health Survey, March 2011
Charlton Research Company for Research!America
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 and health research is conducted?

- Mayo Clinic: 10%
- CDC: 9%
- NIH: 7%
- Johns Hopkins: 6%
- St. Jude: 4%
- Pfizer: 3%
- American Cancer Society: 3%
- Merck: 2%
- Duke Univ./Med. Ctr.: 1%
- OR Heath & Sci. Univ.: 1%
- UCSF: 1%
- Other: 52%

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
Few Americans Recognize the National Institutes of Health

What is the name of the government agency that funds most of the medical research paid for by taxpayers in this country? (first volunteered responses)

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America
Do Americans Know Where Their Elected Officials Stand on Research?
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: 8%
- Somewhat well informed: 25%
- Somewhat uninformed: 7%
- Very uninformed: 24%
- Not sure: 36%

Source: Your Candidates—Your Health Public Opinion Poll, October 2011, JZ Analytics for Research!America
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
Sample Questions to Candidates

• Do you support or oppose making health research sponsored by NIH a higher national priority?
• Do you support or oppose boosting investment in medical research and innovation as a job creation strategy?
• If you are elected, will maintaining America’s global competitive edge in science, technology and innovation be a priority for you?
What Can You Do?

- Talk about return on investment to date in research
- Use in-the-moment news to confirm 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
“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!
Remember the most important four words a researcher can say and convey:
“I work for you.”
Connect With Us

- www.researchamerica.org/blog
- www.researchamerica.org/facebook
- www.twitter.com/researchamerica
- www.youtube.com/researchamerica