Health and Medical Research in the USA in the Era of Sequestration: The Increased Importance of Collaboration and Philanthropy

Mary Woolley, President, Research!America
A Strong Partnership: Research Australia and Research!America

- Since the late 1990s, leadership from Research Australia has visited Research!America and vice versa.
- In November 2012, Research Australia CEO Elizabeth Foley visited Research!America and together, we met with our colleagues from Sweden and Canada.
Partnering in Advocacy

Letter of Agreement Among
Research!America, Research Australia, Research Canada and Research!Sweden

Background

Research!America, Research Australia, Research Canada and Research!Sweden are national health research advocacy organizations whose multi-stakeholder alliances are dedicated to making health research a high national priority in our respective countries. We share a common vision that health research is a shared benefit, a shared responsibility and an investment in each of our countries’ futures.

The four alliances collectively recognize that health research improves the health and prosperity of our nations’ citizens and builds better health systems in our respective countries. We carry out our related missions through advocacy programs that engage broad stakeholder groups, including policymakers, businesses, civil society organizations, and the general public.
Research!America’s Mission

Make research to improve health a higher national priority

Research!America is an innovator in advocacy for research
Research!America: 24 Years of Putting Research on the Public Agenda

- Nonprofit alliance with member organizations drawn from academia, industry, patient organizations and scientific societies representing more than 125 million Americans

- Distinguished, all-volunteer board includes former elected and appointed officials, media, venture capitalists and leaders from alliance member organizations
## Australia and the U.S.

<table>
<thead>
<tr>
<th></th>
<th>Australia</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population (2013 est.)</strong></td>
<td>23,108,000</td>
<td>316,391,000</td>
</tr>
<tr>
<td><strong>GDP</strong></td>
<td>$1.521 trillion USD ($1.704 trillion AUD)</td>
<td>$15.685 trillion USD ($17.608 trillion AUD)</td>
</tr>
<tr>
<td><strong>Total spent on health and medical research</strong></td>
<td>$5.3 billion</td>
<td>$136.245 billion ($152.967 billion AUD)</td>
</tr>
<tr>
<td><strong>Research funding per capita</strong></td>
<td>$229.36 USD ($256.90 AUD)</td>
<td>$430.62 USD ($482.32 AUD)</td>
</tr>
</tbody>
</table>

Source: World Bank; Research Australia; Research!America
U.S. Spends Big on Health Care but Ranks Low in Return on Investment

Source: Organisation for Economic Co-operation and Development; Institute of Medicine
Research Spending in the U.S.

- Total spending: $136.24 billion USD
- Philanthropic spending: $1.077 billion USD
- Biomedical and health research accounts for less than 5% of overall health spending

Source: Research!America annual analysis
What Philanthropy Can Do

- Raised awareness and developed better therapies, leading to a 33% decline in breast cancer mortality in the U.S.
- Funded research that mapped breast cancer genomes and identified four distinct sub-types of breast cancer
- $755 million USD invested in 31 years
What Philanthropy Can Do

- Funded researchers who discovered the gene that causes cystic fibrosis
- Teamed with Vertex Pharmaceuticals on Kalydeco, the first drug to address the root cause of cystic fibrosis
- $188 million USD invested in private sector research alone
What Philanthropy Can Do

- Developed major, free resources for researchers around the world: Mouse Brain Atlas, Human Brain Atlas, Spinal Cord Atlas
- $500 million USD investment from Paul Allen since 2003
What Philanthropy Can Do

- Breakthrough Prize in Life Sciences (launched in 2013)
- Founded by Art Levinson, Sergey Brin, Anne Wojcicki, Mark Zuckerberg, Priscilla Chan and Yuri Milner
- Recognizes excellence in research aimed at curing intractable diseases and extending human life
- Five annual prizes at $3 million USD each
What Industry Philanthropy Can Do

• 100% of net profits from the fashion company fund philanthropic causes, including medical research grants

• Since 1985, it has generated more than $800 million for mental health research from the sale of wine and its signature Music Festival for Mental Health in Napa Valley, CA
What Public-Private Partnerships Can Do

BRAIN Initiative

• 2013 presidential initiative: Brain Research through Advancing Innovative Neurotechnologies
• $100 million USD funded by three U.S. government agencies: NIH, NSF, DARPA
• $122 million USD funded through private sector institutions: Allen Institute, Howard Hughes Medical Institute, Kavli Foundation, Salk Institute for Biological Studies; industry is very interested
Are We Getting our Money’s Worth?
Significant Gains in Life Expectancy

- **Australia:**
  - Females: 58.8 (1901-10) to 83.5 (2004-06)
  - Males: 55.2 (1901-10) to 78.7 (2004-06)

- **U.S.:**
  - Females: 48.3 (1900) to 80.1 (2003)
  - Males: 46.3 (1900) to 74.8 (2003)

**Source:** Australian Institute of Health and Welfare; Congressional Research Service
Childhood Cancers are No Longer a Death Sentence

Pediatric cancer survival rates:

- Australia:
  - 1960s: 2%
  - Today: 75%

- U.S.:
  - Early 1960s: around 30%
  - Today: more than 80%

Sources: The Kids’ Cancer Project; Children’s Cancer Institute Australia; *Oncology*; American Cancer Society
Many Countries Are Ramping Up Investment, e.g.

- **China:**
  - Has pledged $308.5 billion USD in biotechnology funding during the next five years

- **Japan:**
  - Stimulus funding in January provided an additional $11 billion USD for science and technology, bringing the fiscal year total to $57 billion

Sources: United for Medical Research; ScienceInsider
“Scientific know-how, the engine of American prosperity, is especially critical amid intense budgetary pressures. Federal investments in R&D have fueled half of the nation’s economic growth since World War II.”

Rep. Jim Cooper (D-TN) and Alan Leshner, PhD
“The countries that are passive in the face of a global economy, those countries will lose the competition for good jobs. They will lose the competition for high living standards. That’s why America has to make the investments necessary to promote long-term growth and shared prosperity.”

President Barack Obama, 24 July, 2013
Research is at Risk

- Arbitrary, across-the-board 10-year cuts, known as sequestration, will devastate U.S. science and prevention efforts
- Potential legislation from the House of Representatives would cut NIH and CDC almost 20% more
- Brain drain from U.S. is escalating
- Few elected officials are comfortable talking about research
Sequestration Wasn’t Meant to Happen in the U.S.

- Part of the Budget Control Act (became law 2 August, 2011)
- Meant as motivation to congressional “supercommittee” to reach consensus in reducing deficit
- Supercommittee failed (21 November, 2011)
- After numerous attempts to forestall it, sequestration took effect 1 March, 2013
Sequestration: What It Means

- $1.1 trillion USD cut, split between defense and non-defense discretionary funding
- 5% across-the-board cut to NIH and other agencies

*Sequestration comes on top of already-enacted severe budget constraints to annual appropriations for 10 years.*
Impact on Research for Health

• In FY13, NIH forced to cut 5% ($1.55 billion USD) from its budget
• Expected to fund 700 fewer new grants
• Cuts will worsen over the next 10 years
• Furloughs and layoffs across the nation
• Patients denied access to clinical trials
• Young scientists leaving the field

Source: NIH
Save Research Campaign

- Intensified advocacy campaign used advertising, op-eds and letters to the editor, visits and emails to Members of Congress, call-in days
- 142 active partners
- Launched after 2012 general election
- #curesnotcuts
- www.saveresearch.org
- Ongoing
“The defense industry is fighting against spending cuts that would bite weapons makers. The National Association of Manufacturers warns that 1 million private sector jobs could be lost if pending cuts to defense spending go through ... A coalition of medical research groups called Research!America is trying to cut through the noise with stark ads likening spending cuts to poison: ‘WARNING: Washington politics just might kill you.’” (Associated Press, 22 November, 2012)
Save Research Campaign
Anger at Congress

“Congressional Approval Falls to 12%” (Wall Street Journal, July 2013)
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

Abraham Lincoln
Earning public trust and support “should not be taken as an easy ride.”

Professor Ian Chubb, 31 July, 2013
Research!America Poll Data

- Commissioning public opinion polls on research issues for more than 21 years:
  - National Polls
  - State-Based Polls
  - Issue-Specific Polls
- 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.
Important for Elected Officials to Listen to Health Professionals

In thinking about threats to your health, how important is it that elected officials at all levels listen to advice from scientists and public health professionals?

- Very important: 51%
- Somewhat important: 36%
- Somewhat unimportant: 5%
- Very unimportant: 2%

Source: National Public Opinion Poll, October 2011, JZ Analytics for Research!America
Officials Aren’t Paying Enough Attention to Deadly Diseases

Do you agree or disagree that elected officials in Washington are paying enough attention to combating the many deadly diseases that afflict Americans?

- Agree: 19%
- Disagree: 59%
- Not sure: 22%

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics in August 2012.
### How Does Investing in Research Stack Up as a Public Priority?

How important a role does each of the following play in creating jobs and fueling the economy?

<table>
<thead>
<tr>
<th>Issue</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Not too important</th>
<th>Not important at all</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supporting small businesses</td>
<td>64</td>
<td>27</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Investing in education</td>
<td>60</td>
<td>29</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Reducing the federal deficit</td>
<td>59</td>
<td>29</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Investing in energy</td>
<td>56</td>
<td>32</td>
<td>6</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Providing tax cuts</td>
<td>49</td>
<td>34</td>
<td>10</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Investing in medical innovation</td>
<td>44</td>
<td>39</td>
<td>10</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Investing in infrastructure</td>
<td>43</td>
<td>38</td>
<td>9</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
Government Research Important to Private Sector Innovation

How important is basic research funded by the federal government to private sector innovation?

- Very important: 25%
- Somewhat important: 16%
- Not too important: 9%
- Not at all important: 8%
- Not sure: 9%

Source: A Research!America online survey of small business owners conducted in partnership with Zogby Analytics in February 2013.
Wide Majority Believes Research is Key to Reducing Health Care Costs

How important is medical research to reducing health care costs?

- Very important: 57%
- Somewhat important: 26%
- Somewhat unimportant: 11%
- Very unimportant: 3%
- Not sure: 3%

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
Nearly Half Say Public Funding of Biomedical Research Isn’t Enough

Roughly one-and-a-half percent of government spending is allocated for biomedical and health research. Would you say that amount is ...

- 27% About right
- 48% Not enough
- 17% Too much
- 9% Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
More than Half of Americans Willing to Pay Tax for Research

Would you be willing to pay $1 per week more in taxes if you were certain that all of the money would be spent on additional medical research?

- Yes: 54%
- No: 28%
- Not sure: 19%

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
Very Important to Fund Research on U.S. Health Care System

How important is it that our nation support research that focuses on improving how our health care system is functioning?

- **48%** Very important
- **39%** Somewhat important
- **5%** Not too important
- **2%** Not at all important
- **7%** Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
Research Institutions Should Work Together

Do you think the institutions conducting medical and health research in this country, such as government, universities, and private industry, should work together to develop new treatments and cures, or not?

94%

Should work together

6%

Should not work together

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America
Current Challenges
Connect Research for Health to Current Public Concerns

- Cost of health care
- Questioning of all public expenditures
- Worries about public deficit
- Importance of job creation, economic growth and competitiveness
- Sequestration

Everyone is looking for solutions.
Research Creates Good Jobs

- In 2012, National Institutes of Health funding created and sustained 402,000 jobs.
- The average wage in the U.S. is $45,790.
- The average wage for a life science worker in the U.S. is $77,620.

Sources: United for Medical Research; U.S. Dept. of Labor Bureau of Labor Statistics
Research Can Help Contain the Daunting Cost of Health Care

NIH Research Funding and Annual Cost of Care for Major Diseases in the U.S.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Cost in Billions ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s Disease</td>
<td>0.15</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>0.12</td>
</tr>
<tr>
<td>Stroke Research</td>
<td>0.32</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>1.24</td>
</tr>
<tr>
<td>Obesity</td>
<td>0.83</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.08</td>
</tr>
<tr>
<td>Hypertension</td>
<td>0.24</td>
</tr>
<tr>
<td>Cancer</td>
<td>5.45</td>
</tr>
<tr>
<td>Total</td>
<td>95.6</td>
</tr>
</tbody>
</table>

Source: “Sequestration: Health Research at the Breaking Point,” Research!America
Young Scientists At Risk

- In 1982, scientists under age 36 comprised 18% of all NIH primary investigators.
- By 2011, scientists under age 36 comprised 3% of all NIH primary investigators.

Source: Society for Neuroscience
Telling Our Story Locally

Sen. Jon Tester (D-MT) and Mary Woolley
In 2012, the National Football League — the primary professional American football league — earned **$9.5 billion USD** in revenue.

That amount would fund all injury-related research at the National Institutes of Health for **more than 14 years**!

Sources: CNN; NIH FY12
Flickr photo by Jeffrey Beall
In 2012-13, the Australian Football League’s total revenue was $425 million AUD.

That amount would fund NHMRC injury-related research for more than 13 years!

Sources: Sydney Morning Herald; NHMRC FY12
THEN... in the early 1900s, infectious diseases such as measles, diphtheria, tetanus and polio claimed the lives of 66% of our children before they turned 14.

NOW... vaccines can prevent our children from ever contracting these diseases.

IMAGINE... our children growing up healthy, free from all childhood infectious diseases.

Source: Centers for Disease Control and Prevention
Remember the most important four words a researcher can say and convey:
“I work for you.”
Connect with Research!America Online

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