Washington is Paying Attention to Biomedical Research: Is the Devil in the Details?

Mary Woolley, President, Research!America
It’s good to be back in North Carolina!

- 1993 state-wide campaign in North Carolina
- Governor James B. Hunt, Jr. proclaimed Sept. 7 - Oct. 8, 1993 “Medical Research Weeks”
- Wake Forest’s Bowman Gray School of Medicine represented by Associate Dean James Thompson
- Campaign objectives:
  - Better acquaint North Carolinians with the progress and promise of medical research
  - Urge citizens to speak up with their research questions
  - Encourage citizens to speak out in support of research
- Project activities included outreach at schools, public libraries and museums, physician and dentist offices, speaker’s bureaus and via the media.

Medical Research Saves Lives!
FY13 Funding in North Carolina

<table>
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<tr>
<th>Agency</th>
<th>Funding (in thousands)</th>
<th>State Rank</th>
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<tbody>
<tr>
<td>National Institutes of Health</td>
<td>$1,037,787</td>
<td>6</td>
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<tr>
<td>Centers for Disease Control and Prevention</td>
<td>$174,550</td>
<td>8</td>
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<tr>
<td>National Science Foundation</td>
<td>$167,130</td>
<td>11</td>
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<tr>
<td>Agency for Healthcare Research and Quality</td>
<td>$6,559</td>
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Source: Battelle and Biotechnology Industry Organization (BIO), Battelle/BIO State Bioscience Jobs, Investments and Innovation, 2014

- NC Population rank: 10th

Source: Batelle; US Census
## FY13 Economic Impact in North Carolina

<table>
<thead>
<tr>
<th>Industry</th>
<th>Employment</th>
<th>Annual Salary</th>
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<tr>
<td>Pharmaceutical</td>
<td>210,916</td>
<td>$90,115</td>
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<tr>
<td>Medical Device</td>
<td>30,517</td>
<td>$55,140</td>
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<td>Research, Testing, and Laboratories</td>
<td>54,495</td>
<td>$85,655</td>
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<tr>
<td>Overall Private Sector</td>
<td>3,223,192</td>
<td>$43,028</td>
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</table>

**Source:** Battelle and Biotechnology Industry Organization (BIO), Battelle/BIO State Bioscience Jobs, Investments and Innovation, 2014
“Despite the recent interest in reining in health care costs, few North Carolinians want to put a cap on spending for medical research. Three in five want the national commitment to be higher, one in two wants his or her representatives in Congress to support greater spending, and the average resident believes that more than one-third of health care expenditures should be dedicated to research.”

—North Carolina Medical Research Public Opinion Survey commissioned by Research!America, October 1993
1993: Important for U.S. to Maintain World Leadership

How important do you think it is that the U.S. maintains its role as a world leader in medical research?

- **Important**: 83%
- **Somewhat Important**: 14%
- **Not Important**: 3%

Source: A Research!America North Carolina Medical Research Opinion Study conducted in partnership with FGI Integrated Marketing, October 1993
Battelle Report Predicts China to Surpass U.S. in R&D

- Growth in China’s economy is likely to propel it to the top position in R&D spending by early 2020s

Source: Battelle and R&D Magazine, December 2013
Only One Third Say U.S. Will Be a Science Leader in 2020

In your view, which of the following will be considered the number one world leader in science and technology in the year 2020?

- United States: 36%
- China: 29%
- India: 5%
- European Union: 4%
- Brazil: 1%
- Not sure: 26%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in August 2014.
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.
The Status Quo is not an Option...

- NIH grant success rates low of 16.8% in FY 2013
- Annual budget sequester in place until 2021
- Labs closing
- Young scientists leaving the field
- Scientists relocating out of the U.S.
- Elected officials threaten to close down some science, e.g., social science and economics; “shrimp on a treadmill”
- China projected to surpass U.S. GDP in three years and U.S. R&D in less than a decade
- Science is essentially invisible to the public and policymakers
“Science right now is exhilarating … [but] the funding is the worst it has been in 50 years, particularly for early-stage investigators who are just getting started. We are very worried about the future of our enterprise in this country. If we do not turn the corner soon, we are going to lose a significant fraction of those investigators who will just give up after a while. That will be a terrible and irreversible tragedy for our future.”
Will Accomplishments Like These Continue?

Nasal Spray with Insulin Equivalent Shows Promise as Treatment for Adults with Mild Cognitive Impairment, Alzheimer’s Dementia

**WINSTON-SALEM, N.C. – Jan. 8, 2015** – A man-made form of insulin delivered by nasal spray may improve working memory and other mental capabilities in adults with mild cognitive impairment and Alzheimer’s disease dementia, according to a pilot study led by researchers at Wake Forest Baptist Medical Center.

Scientists Invent System to Improve Effectiveness of Cancer Surgery

**Winston-Salem, N.C. – Jan. 20, 2015** – With the goal of making it easier for surgeons to detect malignant tissue during surgery and hopefully reduce the rate of cancer recurrence, scientists have invented a new imaging system that causes tumors to "light up" when a hand-held laser is directed at them.

Rapid Testing for Gene Variants in Kidney Donors May Optimize Transplant Outcomes

**WINSTON-SALEM, N.C. – March 24, 2015** – Kidney transplantation outcomes from deceased African-American donors may improve through rapid testing for apolipoprotein L1 gene (APOL1) renal risk variants at the time of organ recovery, according to a new study led by researchers at Wake Forest Baptist Medical Center.
“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, Former Congressman John Edward Porter
Research!America: 26 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 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
What Research!America Does

- Frame the case for research with impact, including the economic case
- Build champions for research in Congress
- Work to assure strong funding and policies for both public and private sector science
- Partner with patient groups and others to amplify the voice for research in the media
- Commission public opinion polls to 1) inform our members and friends, and 2) drive advocacy
- Work with scientists to improve communication with non-scientists
- Combat science doubt
10% increase for NIH in FY16
At least the levels requested by the President for FDA, CDC, AHRQ and NSF.
Advance 21st Century Cures initiative
Repeal medical device tax
Make R&D tax credit permanent
End sequestration
Build champions for research in Congress
Talking up NIH on Capitol Hill

Flurry of Legislation Introduced to Boost NIH Funding, including:

- **Permanent Investment in Health Research Act**
  - Castor/Butterfield - HR 777
  - Would give NIH funding a permanent funding stream outside appropriations, at level of GDP

- **Accelerating Biomedical Research Act**
  - DeLauro/Higgins/King - HR 531 [bipartisan]
  - Mikulski/Cardin - S. 318
  - Would permit an exemption from overall budget caps to achieve sizeable growth in NIH funding over the next decade.
More from Capitol Hill

- Medical Innovation Act
  - Van Hollen/Schakowsky/Welch/Castor - HR 744
  - Warren/Cardin/Brown/Baldwin - S. 320
  - Would create a trust fund to significantly supplement annual appropriations for NIH and FDA

- America Cures Act
  - Durbin/Franken/Cardin (etc.) - S. 289
  - Would create trust fund to significantly supplement annual appropriations for NIH, CDC, the DOD Health Program and the VA Medical and Prosthetics Research Program
Speaking in defense of ‘regular order’: “When you don’t debate and defend your priorities, you forget what they are ... people lose track of the good things we are spending our money for.”

Senator Roy Blunt (R-Mo.), Chairman, Senate Labor-HHS Appropriations Subcommittee
21st Century Cures Initiative

- Reps Upton (R-MI) DeGette (D-CO) launched initiative on 5/1/14, with focus on:
  - Integrating the patient’s perspective
  - Modernizing clinical trials
  - Fostering the future of science, including encouraging young scientists
  - Investing in advancing research
  - Incentivizing the development of new drugs and devices for unmet medical needs
  - Supporting 21st century digital medicine by facilitating data sharing and the use of new technologies

- Senators Alexander (R-TN) and Burr (R-NC) launched companion initiative on 1/29/15
Broad Significance of 21st Century Cures

- Has propelled medical progress into the spotlight.
- Demonstrates that better health transcends partisanship, civility is a possibility, and gridlock need not be the rule.
- A welcome counterweight to attacks on science. Connects the dots between discovery, development and delivery - “we are all in this together.”
- Provides a rare platform for addressing issues that too often get lost in the shuffle (Borrow the momentum!).

“The draft bill, now officially in the public domain for additional input and modification, could be a game-changer for the medical innovation ecosystem.”

Statement by Research!America President and CEO Mary Woolley on 21st Century Cures Initiative Discussion Draft Jan. 27, 2015
What’s Missing from 21st Century Cures?

- Adequate funding for the federal health agencies to implement provisions in 21st Century Cures.
- Provisions to address gaps in safety and efficacy testing, including for subgroups
- Defined roles for AHRQ and PCORI
- Provider Reimbursement for Discussing Research
“Devil in the Details”

- New agency responsibilities require new resources
- Speedier access must not come at expense of sound measurement of safety and efficacy - Medical advances that do more harm than good are not really advances
- Accountability is appropriate; politicizing/micromanaging allocation of NIH dollars is not
- Strict standards for “real world data” essential; not a substitute for traditional clinical trials
- Modifying HIPPA to enable more research makes sense, but privacy is still important
- More resources for urgent issues like antibiotic resistance and Alzheimer’s is important - but watch out for ‘robbing Peter to pay Paul’
U.S. Politicians Rarely Talk about Research: Why?

- Many fear being asked science questions they can’t answer
- Their constituents aren’t pressing them for action
- They take progress in research for granted
- Some are opposed to government’s role in science

Sometimes, politicians do find their voices about research... advocacy helps make that happen!
“I've been recognized by numerous groups as one of the most tight-fisted people in the entire Congress … That having been said, I believe with all my heart and soul that if the federal government doesn't lead the way on conquering cancer that it won't get done.”

Launch of One Degree Campaign, Capitol Hill, March 17, 2015

Rep. Matt Salmon (R-Ariz.), member, Education and the Workforce Committee
"Why aren't we spending $60 billion in NIH research? Honestly. I'm not a big fan of deficit spending. I'm not a big fan of deficits. Certainly, as a conservative Republican, I believe the fiscal health of our nation is one of the most critical issues long term. But I think I can go to my 16-month old daughter and I can say, 'I borrowed money in your name to cure cancer' and she would thank me."

Launch of One Degree Campaign, Capitol Hill, March 17, 2015

Rep. Kevin Yoder (R-Kan.), member, House Appropriations Committee
“...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 22 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.
Majority 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.”

- 24% Strongly agree
- 46% Somewhat agree
- 15% Somewhat disagree
- 11% Strongly disagree
- 4% Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Nearly Half Support Use of Animals in Medical Research

Do you believe the use of animals in medical research is necessary for progress in human health?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Support Declining for the Use of Animals in Medical Research

Do you believe the use of animals in medical research is necessary for progress in human health?

- **Jan. 2015**: 46 Yes, 27 No, 27 Not sure

- **Oct. 2011**: 50 Yes, 28 No, 21 Not sure

- **2008**: 67 Yes, 33 No, 4 Not sure

- **2004**: 77 Yes, 19 No, 4 Not sure

Source: National Public Opinion Polls, 2004 to 2015
How important is it that elected officials at all levels listen to advice from scientists?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Public Perceptions of Science and Scientists are Favorable

According to the latest National Science Board poll:

- Nearly 80% of Americans say leaders of science and medicine inspire confidence among the public. Only military leaders are ranked higher.
- Nearly 80% say they would be happy if their son or daughter chose science as a career.

National Science Board Science and Engineering Indicators, 2014
Most Trusted Spokespersons for Science?

How trustworthy do you consider each of the following to be as spokespersons for science?

- **Scientists**: 33% Very trustworthy, 48% Somewhat trustworthy, 9% Not very trustworthy, 9% Not at all trustworthy, 12% Not sure
- **Health care professionals**: 24% Very trustworthy, 52% Somewhat trustworthy, 12% Not very trustworthy, 9% Not at all trustworthy, 16% Not sure
- **Patient organizations**: 19% Very trustworthy, 47% Somewhat trustworthy, 16% Not very trustworthy, 15% Not at all trustworthy, 11% Not sure
- **Journalists**: 8% Very trustworthy, 34% Somewhat trustworthy, 32% Not very trustworthy, 16% Not at all trustworthy, 11% Not sure
- **Bloggers**: 7% Very trustworthy, 21% Somewhat trustworthy, 37% Not very trustworthy, 20% Not at all trustworthy, 15% Not sure
- **Business leaders**: 7% Very trustworthy, 31% Somewhat trustworthy, 34% Not very trustworthy, 16% Not at all trustworthy, 13% Not sure
- **Elected officials**: 5% Very trustworthy, 16% Somewhat trustworthy, 34% Not very trustworthy, 33% Not at all trustworthy, 12% Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014
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

Please name a living scientist.

- I can: 30%
- I cannot: 70%

**Names mentioned:**
- Stephen Hawking 43%
- Neil Degrasse Tyson 6%
- Bill Nye 5%
- Jane Goodall 5%
- James Watson 3%
- Richard Dawkins 2%
- Michio Kaku 2%
- Mehmet Oz 1%
- Other 33%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
Do Americans Know Where Research is Conducted?
Most Americans Don’t Know Where Research is Conducted

Please name any institution, company or organization where medical or health research is conducted.

56%

44%

I can

I cannot

Mayo Clinic 14%
Johns Hopkins 14%
CDC 8%
NIH 6%
Pfizer 4%
Cleveland Clinic 3%
St. Jude’s 2%
American Cancer Soc. 2%
Harvard University 2%
Duke University 1%
Eli Lilly 1%
Other 43%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
Do Americans Know Which States Research is Conducted in?
Only 1 in 4 Americans Know Research is Conducted in Every State

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

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Do Americans Recognize the NIH?
What is the name of the government agency that funds most of the medical research paid for by taxpayers in this country?

- National Institutes of Health: 16%
- Food and Drug Administration: 16%
- Dept. of Health and Human Services: 15%
- Centers for Disease Control and Prevention: 19%
- Other: 1%
- Don't know: 33%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014.
Only Half Agree Research has Benefited Family’s Health

Would you say your family’s health has been improved by medical research?

- Yes: 53%
- No: 22%
- Not Sure: 25%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
WARNING: Failure to be an advocate can be hazardous to your research career
What Can You Do?

• Talk about aspirations for research, and the return on investment
• Emphasize how research drives economic activity in every state and creates good jobs
• Convey your personal commitment
• Encourage your colleagues to engage the public
• Remember the four most important words...
A Challenge: Pass the Starbucks Test
North Carolina’s Congressional Delegation, 114th Congress

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<tr>
<th>Senate</th>
<th>House</th>
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<tr>
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<td>E&amp;C Committee</td>
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<tr>
<td>Sen. Thom Tillis (R)</td>
<td>Rep. Renee Ellmers (R-NC-02)</td>
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<td>Rep. Alma Adams (D-NC-12)</td>
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<td>Rep. George Holding (R-NC-13)</td>
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<td>Ways and Means Committee</td>
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A Specific ‘Ask’

House and Senate NIH Sign-On Letters

Sen. Richard Burr (R-NC) & Sen. Bob Casey (D-PA) co-leading the sign-on effort

Co-signers from NC:

- Sen. Thom Tillis (R-NC)
- Rep. David Price (D-NC-04)
- Rep. Alma Adams (D-NC-12)
- Rep. Mark Walker (R-NC-06)
- Rep. G.K. Butterfield (D-NC-01)

*Goal: all members of NC delegation sign on*
Many Scientists Unsure How to Engage in PCST

Young scientists surveyed gave the following reasons for not engaging in public communication of science and technology (PCST):

- Don’t know how: 73%
- Unaware of opportunities for public engagement: 63%
- Don’t have necessary training: 50%
- Lack of time: 38%
- Absence of credit toward professional development: 8%
- Other: 2%

Source: Young Scientist Survey, Winter 2012—Research!America
How to Think About Communication to Non-Scientists

- Know your audience
- Use the Then-Now-Imagine message frame
- Be in the moment
- Understand and align with public sentiment
- Convey personal commitment/passion

*Communicating well demonstrates accountability*
Tell Your Story, Not Your Data!

“I'll pause for a moment so you can let this information sink in.”
“What you understand well can be communicated well. It's a matter of not just discipline but obligation to the public for scientists to communicate both the excitement of science, the prospects of science and the accomplishments of science.”

Elias A. Zerhouni, MD, President, Global Research & Development, Sanofi, and former NIH Director
THEN... In 1981, the Centers for Disease Control and Prevention noted the first cases of what would become the AIDS epidemic. **AIDS IS A DEATH SENTENCE.**

NOW... NIH-funded research supported the development of a microfluid-based “lab-on-a-chip” to rapidly detect HIV. **HIV/AIDS IS A MANAGEABLE CHRONIC DISEASE.**

IMAGINE... A vaccine. **HIV/AIDS IS RELEGATED TO THE HISTORY BOOKS.**

Research is the future!
In 2014, $15.9 billion was spent on Easter in the United States.

That amount could fund NIH sponsored Alzheimer’s research for more than 28 years!

Sources: National Retail Federation; http://report.nih.gov/categorical_spending.aspx
“... If I had to do it all over again, I would spend more time talking to general audiences and public officials, penning op-eds.”

J. Michael Bishop, MD, Nobel laureate
“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
It’s Time to Put a Face on Research: YOURS!
Remember the most important four words a researcher can say and convey:
“I work for you.”
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www.researchamerica.org/blog
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www.twitter.com/researchamerica
www.youtube.com/researchamerica
www.researchamerica.org/askyourcandidates