21st Century Research for Women’s Health

March 9, 2015

ACOG’s 33rd Annual Congressional Leadership Conference, Washington, D.C.
My Purpose Today

- Introduction to Research!America
- Comments on 21st Century Cures
- Other developments of interest
- Relevant public opinion poll data
- An exhortation to advocacy
Our Vision

Achieve national commitment to pursuing medical and health research at the highest level of scientific opportunity in both the public and private sectors, to assure medical progress.
Research!America: 26 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 Goals

- Achieve funding for research at the level of scientific opportunity
- Advocate a policy climate that stimulates rather than impedes research and development
- Empower members of the stakeholder community to advocate for research
- Ensure that the public hears about research benefits and success stories: Research must not become invisible!
Recent Ad Campaigns

SOME CONSTITUENTS ARE VOCAL. OTHERS NEED OUR VOICE.

SUPPORT FUNDING FOR PEDIATRIC RESEARCH.
The high incidence of preterm births and resulting complications remain a major health concern in the U.S. The complex nature of preterm birth requires additional research on the biological and psychosocial causes of, and treatments for, prematurity to address this serious medical problem.
Current Research!America Advocacy Agenda

- 10% increase for NIH in FY16
- Robust Increases for FDA, CDC, AHRQ and NSF
- Achieve the 21st Century Cures vision
- Medical device tax repeal
- Make R&D tax credit permanent
- End sequestration and prevent other damage to research
- Build champions for research in Congress
- Freshmen and general Hill Briefings
- Advance policies to spur private sector innovation
- Contribute to relevant current legislative issues
21st Century Cures Initiative

- Draft legislation released with a goal of completion by end of the year
- Six priorities:
  - Integrate the patient’s perspective
  - Modernize clinical trials
  - Foster the future of science, including encouraging young scientists
  - Invest in advancing research
  - Incentivize the development of new drugs and devices for unmet medical needs
  - Support 21st century digital medicine by facilitating data sharing and the use of new technologies

Source: http://energycommerce.house.gov/cures
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
“We believe open and transparent communication of important scientifically accurate data is important to advancing medical treatments in the digital age ... In particular, subgroup analysis can shed light on important sex differences that will help physicians tailor treatments differently to their male and female populations.”

Comments from the Society for Women’s Health Research to the Energy and Commerce Committee

Jan. 27, 2015
What Else is 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 Clinical Trial Recruitment and Enrollment.
Another Important Activity This Spring

- AcademyHealth Spring Meeting on Maternal Health and Health Services Research
- Purpose: Develop agenda on key research and policy issues
- ACOG should be there!
The Public is Paying Attention

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

President Abraham Lincoln
Americans see U.S. leadership slipping in health care

Do you believe the United States has the best health care system in the world?

- Yes: 27%
- No: 52%
- Not sure: 21%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
In your view, which of the following will be considered the number one world leader in health care in the year 2020?

- United States: 39%
- China: 5%
- India: 2%
- European Union: 20%
- Brazil: 1%
- Not sure: 33%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in August 2014.
More Men Say U.S. Will Be #1 Health Care Leader in 2020

In your view, which of the following will be considered the number one world leader in health care in the year 2020?

- Women: 34 United States, 52 China, 19 India, >1 European Union, 40 Brazil, 2 Not Sure
- Men: 44 United States, 43 China, 20 India, 1 European Union, 27 Brazil, 1 Not Sure

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

- Commissioning public opinion polls on research issues for 23 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.
Most Americans Have Not Participated in Clinical Trials

Have you or anyone in your family ever participated in clinical trials?

- Yes: 16%
- No: 77%
- Not sure: 7%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
If your doctor found a clinical trial for you and recommended you join, how likely would you be to participate in a clinical trial?

- Very likely: 46%
- Somewhat likely: 13%
- Not likely: 12%
- Would not participate: 3%
- Not sure: 13%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
More Men than Women Say Doctors Have Talked About Medical Research

Has your doctor or other health care professional ever talked to you about medical research?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
More Men than Women Believe Health Care is Based on Latest Research

Do you believe that the health care services you receive are based on the best and most recent research available?

Source: A Research!America poll of U.S. adults conducted in partnership with JZ Analytics in December 2012.
Many More Men than Women Say Research is Part of the Solution

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?

Many More Men than Women Say Research is Part of the Solution

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<td>Not sure</td>
<td>24</td>
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Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Women More Likely to Share Personal Health Information to Advance Medical Research

For which of the following would you be willing to share your personal health information (Choose all that apply)?

- So health care providers can improve patient care
  - Women 64%
  - Men 56%

- To advance medical research
  - Women 60%
  - Men 49%

- So public health officials can better track disease and disability and the causes
  - Women 48%
  - Men 45%

- None
  - Women 8%
  - Men 13%

- Not Sure
  - Women 10%
  - Men 15%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Physicians, Internet are Primary Sources of Info on Clinical Trials

Where would you go to get information about clinical trials? (multiple responses allowed)

- My doctor: 60%
- Online: 57%
- Hospitals: 27%
- Pharmaceutical companies: 25%
- Patient organizations: 18%
- Government institutions: 16%
- Foundations/charities: 16%
- Friends or family: 14%
- Other: >1%
- Not sure: 15%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
Doctors Should Educate the Public on Clinical Trials, Americans Say

Which organizations listed below would you say has the greatest responsibility in educating the public about clinical trials?

- Federal gov't: 17%
- Doctors and other health care providers: 41%
- Insurance companies: 4%
- Pharmaceutical companies: 16%
- Patient organizations: 6%
- Not sure: 16%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
What Else 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 with elected officials
- Remember the four most important words ...
“I work for you.”
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