A Budget Deal for FY13 and FY14? From Long Shot to Likely

With the December 13 deadline for a bipartisan 2014 budget plan looming, the Budget Conference Committee, chaired by Sen. Patty Murray (D-WA) and Rep. Paul Ryan (R-WI), has struck a tentative deal on overall discretionary funding levels for FY14 and FY15. Reportedly, this agreement, if signed into law, would reduce the sequestration cuts by $50-$60 billion over the two-year period as reflected in higher overall budget caps. This relief would be spread evenly across defense and non-defense spending categories. A combination of other budget cuts and increased fees would be enacted to offset the savings lost due to the reduction in sequestration.

As of this writing there is a strong chance this deal will pass, despite resistance from House Democrats who are threatening to vote against the deal unless it is coupled with an extension of unemployment benefits as part of this package. While in the minority, House Democrats will play an influential role Continued on page 4

New Poll: Americans Believe Another Government Shutdown is Likely

A new national public opinion poll commissioned by Research!America and the American Society of Hematology found that nearly two-thirds of Americans say it’s likely there will be another government shutdown in the months ahead as Congress continues to debate deficit and budget issues. The survey also found that government dysfunction has consequences: A majority of Americans (57%) say the shutdown in October caused significant harm to many government-funded programs including medical research, defense and education.

A plurality (44%) says Congress must tackle tax and entitlement reform to reduce the deficit instead of continuing sequestration; another 16% say sequestration is not the right way to reduce the deficit. In general, 62% of Americans say they’re concerned about the long-term effects of sequestration on advances in health care such as the development of new drugs and other treatments.

“Our poll demonstrates uneasiness among many Americans about the ramifications of deep spending cuts to programs that are critical to our health and well-being,” said Mary Woolley, president and CEO of Research!America. “Americans want Congress to reach a budget deal that protects medical and health research, at least in part because of concern that our nation is at risk of losing our global leadership position in science and innovation.”

Continued on page 5

Less Than A Third Believe U.S. Will Be a Science Leader in 2020

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>United States</td>
<td>27%</td>
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<tr>
<td>China</td>
<td>33%</td>
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<tr>
<td>India</td>
<td>5%</td>
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<td>European Union</td>
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<tr>
<td>Brazil</td>
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<tr>
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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. (TOTALS DO NOT ADD TO 100% DUE TO ROUNDING.)
In 1997, a year after the gene that causes Friedreich’s ataxia was identified, Ron and Raychel Bartek received the diagnosis of their son, Keith, and discovered that there was no treatment for the disease and no group dedicated to finding one. So they started FARA. Since then, FARA alone has funded more than $20 million in research on the disease and helped secure a similar amount from co-funding organizations. That has helped lead to multiple clinical trials encompassing a range of treatment approaches.

FARA President Ron Bartek remembers when he and his wife decided to start a nonprofit dedicated to finding a treatment for Friedreich’s ataxia.

“On the night we received Keith’s diagnosis, we saw online there was no treatment, very little research into the disease and no organization devoted entirely to supporting such research. We were living in the DC suburbs, we were 30 minutes from the [National Institutes of Health], and we both worked on Capitol Hill,” he recalled.

“Maybe we’re supposed to do this.”

Things moved quickly after that: On the day FARA was approved for incorporation, Bartek drove to the NIH to apply for a workshop grant. A friend helped them quickly attain 501(c)(3) status; with that secured, the NIH approved the workshop grant. Two months later, FARA co-hosted with the National Institute of Neurological Disorders and Stroke the world’s first Friedreich’s ataxia workshop. Sixty-five scientists from around the world joined 15 NINDS researchers for that first conference.

Though a treatment remains elusive, that’s about the only thing that hasn’t changed. The last conference on Friedreich’s ataxia was held in Strasbourg, France; 200 people attended, and many others were turned away due to space limitations. Pharmaceutical companies and advocacy organizations were well-represented. The Barteks’ initial goal was being accomplished.

“That was our first objective: to grow the field,” Bartek said.

Most importantly, an approved treatment may be near at hand—with others following along and providing a “cocktail therapy” to treat the disease effectively and eliminate it in subsequent generations.

Research!America’s obvious effectiveness at advocacy is a critical reason why FARA is a member.

“Research!America is a key advocacy organization in support of medical and health research across the front. They’re so effective at the highest levels and in collaborating with other advocates,” Bartek said. “With all of us pulling together, we’re such a powerful voice.”


Research!America adds value for our members:

- Research!America leadership is frequently quoted by local, national and trade media. The stories that result help demonstrate the importance of research to improve health and spread the message to audiences across the country.
- Research!America’s Advocacy Awards celebrate the efforts of those who have made a difference in advocating for or increasing awareness of the role of health and medical research.
Winning Hearts, Minds and Votes for Science
Research!America President and CEO Mary Woolley’s op-ed in The Scientist stressed the need for scientists to play a role in winning the hearts and minds of voters by making a personal connection. “Everyone must start today to put a human face—your face—on science. Start today to convey your commitment to serving the public’s interest,” Woolley wrote.

Surgeon General Nomination
Research!America Board member Elizabeth Nabel, MD, president of Brigham and Women’s Hospital, was quoted in The Boston Globe in support of Surgeon General nominee Vivek Murthy, MD. Nabel was also interviewed in CQ Healthbeat about the nomination along with Research!America Board member Georges Benjamin, MD, executive director of the American Public Health Association.

Public Health Thank You Day
Several op-eds and letters to the editor about Public Health Thank You Day—celebrated on November 25—ran in various media outlets across the country. James A. Madson, RN, MPH, director of the Beaufort County (NC) Health Department, wrote an op-ed for Beaufort County Now saluting public health workers who perform the hard work done “in the trenches.” Nola Aigner, public information officer at the Cerro Gordo County (IA) Department of Public Health, wrote an op-ed for the Globe Gazette that highlighted the dedication of disease prevention and food safety health officials in keeping county residents healthy.

A letter to the editor in the York (PA) Daily Record by Barbara Kovacs, director of the York City Bureau of Health, acknowledged “public health professionals, whose day-to-day work rarely garners headlines, dedicate their careers to keep us safe and healthy.”

Public Health Thank You Day articles were written for American Public Health Association’s Public Health Newswire, the Robert Wood Johnson Foundation blog New Public Health, the Association of Public Health Laboratories blog LabLog, and the University of Wisconsin-Madison School of Medicine and Public Health website.

Supporting Research Collaboration
Margaret Anderson, executive director of FasterCures, noted that collaboration in medical research “is a game changer” in an op-ed for The Huffington Post. “Congress needs to prioritize medical research and innovation to even stay in the game,” Anderson wrote.

Sen. Casey’s Support for Research
Mary Woolley’s letter to the editor was published in The Philadelphia Inquirer about Sen. Bob Casey’s (D-PA) recent visit to the University of Pennsylvania. She urged other elected officials to also demonstrate attention and support for medical research. “Adequately supported, research will allow us to overcome major health threats and drive the economy,” Woolley wrote.

Mary Woolley Discusses Research!America’s Anniversary
Mary Woolley was profiled in WashingtonExec about the 25th anniversary of Research!America and her tenure with the organization. “We can save so many more lives and we can save money in our health care system if we really do put research to work,” Woolley noted.
A Budget Deal for FY13 and FY14? From Long Shot to Likely Continued from page 1

in the outcome of this process, since their votes—in conjunction with likely opposition from some House Republicans to any reduction in non-defense discretionary sequestration—could prevent passage of the budget deal. However, there is strong evidence that few policy makers on either side of the aisle are willing to contribute to another government shutdown.

If overall budget numbers can be agreed upon, the question becomes whether appropriators can negotiate individual spending bills to prioritize funding under the cap. It is likely that only a few bills will be negotiated and that the bills that allocate funding for the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, and the Agency for Healthcare Research and Quality will not be among them. In that case, the best case scenario for NIH and FDA may be a slight increase over FY13, and the best case for CDC and AHRQ may be flat funding, leaving the 2013 sequestration cuts largely in place.

If no budget agreement is reached, policy makers must pass another continuing resolution (short- or long-term) that—unless controversial shifts in funding are included as “anomalies”—would continue to flat fund virtually all discretionary programs.

As anticipated, the Conference Committee did not wade into tax and entitlement reform, a policy imperative that remains so highly charged that progress will likely require significant debate and negotiation.

Last year, there was no discussion of reducing or eliminating the 2% sequestration cut to Medicare in FY14 and in FY15. These cuts pose a threat to reimbursement rates for prescription drugs, biologics and medical devices, as well as for providers such as academic health centers. Any reduction in reimbursement could easily have iterative effects on clinical research and private sector R&D in the biomedical arena.

CPH Foundation Update

As of press time, The CPH Foundation was preparing to announce its 2013 Unsung Heroes of Public Health. A day of congressional visits and a reception in honor of the awardees will take place January 8. Awardees visit with Members of Congress and their staffs, as well as committee staff, to help demonstrate the good work being done by public health leaders across the country.

Please plan to stop by the Gold Room (Room 2168) of the Rayburn House Office Building between 4-6 p.m. to meet this year’s winners.

CPHF is also working with partners on Capitol Hill to hold a briefing on hepatitis C. Please visit our website, www.cphfoundation.org, for details.

<table>
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<th>Agency</th>
<th>FY12 Actual</th>
<th>FY13 Post-Sequestration</th>
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* CDC core budget
** Excludes funding from transfers
Sequestration Impact: NIH Says It Funded 640 Fewer Grants

The National Institutes of Health has announced a revision of grant funding data: 640 fewer grants were funded because of sequestration in FY13. The number, which was updated in early November, appears on the NIH fact sheet explaining the impact of sequestration on the agency.

According to the fact sheet, the $1.55 billion lost to sequestration also meant 750 fewer new patients admitted to the Clinical Center as well as delays in medical progress and less support to the scientific workforce.

Download the full fact sheet at http://1.usa.gov/16VpXkE.

Sequestration Impact Reports from American Heart Association, NDD United

The American Heart Association and NDD United have produced reports further detailing the impact of sequestration on health and medical research.

AHA’s booklet, “Sequester Stories: How Heart and Stroke Research Hangs in the Balance,” tells the stories of seven researchers from across the country who have been directly affected by sequestration. One of them, Heather Duffy, PhD, is a distinguished researcher who was forced out of science because she was unable to secure funding.

“I was given some funds to hold me through one more grant cycle, but the payline dropped again and I lost my entire career,” Duffy said in the booklet. “I also watched as my young colleagues grew despondent and dropped out as well. I could no longer tell my students that this was a good career for them so I walked away. I was not the only one.”

The NDD United booklet, “Faces of Austerity: How Budget Cuts Have Made Us Sicker, Poorer, and Less Secure,” shows the impact of sequestration on a range of government programs. One chapter delves into the effects on science.


Survey: Research, Personnel, Students Already Affected by Sequestration

In a survey of 171 leaders from public and private research universities, 81% agreed that sequestration had already impacted research activities at their school; 58% said that their school’s personnel have been affected by sequestration; and 42% said sequestration has directly impacted students at their schools.

The survey was sponsored by the Association of American Universities, the Association of Public and Land-grant Universities, and The Science Coalition.

Beyond the obvious effects on research and the workforce conducting that research, those surveyed also noted the impact on manufacturers—multiple respondents identified reductions or cancellations in equipment purchases—but also on American competitiveness.

“Some graduate students have dropped out of programs this year or are considering leaving in favor of consulting, startups and other non-academic careers,” one university leader commented in the survey.

To see more results, visit http://bit.ly/1etU7BH.

Americans Believe Another Government Shutdown is Likely

Continued from page 1

The poll shows nearly three-quarters (73%) of Americans doubt the U.S. will be the number one world leader in science and technology in 2020, a significant increase from last year (59%). Many believe the federal government must increase investments in medical and health research now to ensure that the U.S. can compete globally (61%), and a vast majority (84%) think it’s important for the U.S. to lead in medical, health and scientific research.

More results from the poll are available at http://bit.ly/1bG5WWX.

SPECIAL THANKS TO OUR RENEWING RESEARCH!AMERICA ALLIANCE MEMBERS

NEW MEMBERS
- Cubist Pharmaceuticals, Inc.
- Florida International University Herbert Werthein College of Medicine
- Gilead Sciences, Inc.
- TEVA Pharmaceuticals
- University of Georgia

RENEWING MEMBERS
- American Diabetes Association
- American Geriatrics Society
- American Pediatric Society
- American Sociological Association
- Association of University Research Parks
- Bristol-Myers Squibb
- California Institute for Regenerative Medicine
- CryerHealth, LLC
- Dana-Farber Cancer Institute
- Emory University Rollins School of Public Health
- FasterCures
- The Feinstein Institute for Medical Research
- The Foundation Fighting Blindness
- Genetics Policy Institute
- Georgia Research Alliance
- Institute of Electrical and Electronics Engineers (IEEE-USA)
- Lilly
- Massachusetts Institute of Technology
- Mylan Specialty L.P.
- Northeast Ohio Medical University
- Pennsylvania State University
- College of Medicine
- Siemens Medical Solutions USA, Inc.
- The Society for Women’s Health Research
- Texas Biomedical Research Institute
- University at Buffalo School of Medicine and Biomedical Sciences
- University of Louisville
- University of Pittsburgh School of Nursing
- The University of Texas MD Anderson Cancer Center
- Wayne State University
- Weill Cornell Medical College

Alan Leshner, PhD, chief executive officer of the American Association for the Advancement of Science and a Research!America Board member, has been named to the new Global Learning Council at Carnegie Mellon University.

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Research!America extends special thanks to our principal partners:

**2014 Advocacy Awards**
Benefactor:
Hogan Lovells US LLP
Susan Whitehead

**National Health Research Forum**
American Association of Colleges of Pharmacy

**Research Matters Communications Workshop**
Sponsor:
Society for Neuroscience

**Polling Partner**
Zogby Analytics

Visit www.researchamerica.org/partnership_opportunities for ways to support Research!America.

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Warren Calls for Doubling the NIH Budget

Sen. Elizabeth Warren (D-MA) said that Congress should double the budget of the National Institutes of Health to better serve medical progress and American competitiveness. Warren made the comments during a forum of the Greater Boston Chamber of Commerce, according to the Associated Press.

Refusing to invest in the NIH, she said, is “the budgetary equivalent of cutting off your feet to save money on shoes.”

Massachusetts has lost $128 million in research funding alone because of sequestration, Warren said during her remarks.

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Survey: More Funding for Genetic Causes of Disease

A survey by researchers at Syracuse University and Yale University found that 57% of respondents think the federal government should spend more to research the genetic causes of disease. The survey, which was published in Genetics in Medicine, also polled respondents on the Genetic Information Nondiscrimination Act of 2008 as well as direct-to-consumer genetic testing.

Rene Almeling, PhD, of Yale, and Shana Kushner Gadarian, PhD, of Syracuse, authored the article.

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Public Health Thank You Day Reaches Wide Audience

Research!America and our partners marked Public Health Thank You Day on November 25—and the message spread across, and even beyond, the country.

In all, messages about Public Health Thank You Day reached more than 350,000 Twitter users; Centers for Disease Control and Prevention Director Tom Frieden, MD, MPH, tweeted about the day and was quoted in the national press release. Between Facebook and Twitter, groups from 18 states and Canada made mention of the day. And more than 1,900 people visited the Public Health Thank You Day website, which is hosted on Research!America’s website.

Research!America’s partners for Public Health Thank You Day included the Campaign for Public Health Foundation, the American Public Health Association, the University of Wisconsin School of Medicine and Public Health, the Johns Hopkins Bloomberg School of Public Health, the American Association of Public Health Dentistry, the University of Alabama at Birmingham School of Public Health, the Ohio State College of Public Health, the Society for Public Health Education, the University of North Carolina Gillings School of Global Public Health, and the National Alliance for Hispanic Health.

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AMERICA SPEAKS

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
43%

No
34%

Not sure
23%

IDF Report: Worldwide Battle Against Diabetes “Is Being Lost”
The International Diabetes Federation has released the sixth edition of the IDF Diabetes Atlas, which concludes that a record 382 million people—a prevalence rate of 8.4%—across the globe are living with diabetes. IDF estimates that by 2035, the number of diabetes cases will reach 592 million.

“The battle to protect people from diabetes and its disabling, life-threatening complications is being lost,” the federation said.

The report was sponsored by the diabetes divisions of Eli Lilly and Sanofi, as well as Merck, Novo Nordisk and Pfizer.


Murthy Nominated to Become Surgeon General
Vivek Murthy, MD, a hospitalist at Brigham and Women’s Hospital in Boston and a professor at Harvard Medical School, has been nominated to become U.S. Surgeon General. The White House announced the nomination of Murthy and a handful of others in mid-November.

“We share a belief that access to quality health care is a basic human right,” Brigham and Women’s President and Research!America Board member Elizabeth Nabel, MD, said in a statement about Murthy to The Boston Globe. “I am confident that he will be a passionate advocate and that he will have an extraordinary impact as our nation’s surgeon general.”

Murthy must be confirmed by the Senate. He would replace Regina Benjamin, MD, who stepped down from the position in July after serving four years.

Study: Neglected Diseases Still Largely Neglected
A recent study from The Lancet Global Health has found that despite significant progress in the past decade, drugs and vaccines for neglected diseases only account for a fraction of new treatments. The study—conducted by Drugs for Neglected Diseases initiative, Doctors Without Borders, the World Health Organization’s tropical disease research branch and others—found that of the 850 new treatments approved in the past 12 years, only 4% were for neglected diseases. That was an improvement since the previous study in 2002, when the survey found that only 1% of all pharmaceutical research focused on neglected diseases. The study also found that while most of the research done is supported by governments and philanthropy, an increasing amount—now almost a quarter—is conducted by private industry. The authors, who considered a total of 49 diseases to be neglected, found that vaccines make up more than half of the new products in development.

Important to Fund Research on U.S. Health Care System

<table>
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<th>Importance</th>
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<tr>
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<tr>
<td>Not sure</td>
<td>10%</td>
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How important is it that our nation supports research that focuses on improving how our health care system is functioning?

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. (TOTALS DO NOT ADD TO 100% DUE TO Rounding.)
Coming UP


Advocacy & Action

Sequestration Must Be Eliminated

To protect medical and health research, policy makers must eliminate sequestration.

This remains Research!America’s top-line message; it is sequestration that poses the greatest threat to all discretionary funding, including medical and health research conducted by NIH, CDC, FDA, NSF, AHRQ, DOD … and the list goes on. Advocates for medical and health research have made a huge impact over the years on funding and policies supportive of medical and health research, including playing a key role in reducing sequestration in 2013. Tell your lawmakers to protect medical research in these final weeks of budget negotiations while preventing another government-wide shutdown.

Visit US ON THE WEB www.researchamerica.org

Connect with Research!America Online
Follow us on Twitter: www.twitter.com/researchamerica
Become a fan on Facebook: www.researchamerica.org/facebook
Watch our YouTube channel: www.youtube.com/researchamerica
Visit our blog: www.researchamerica.org/blog
Research & Innovation:
Georgia

Georgia Health Facts
- Cancer and heart disease each kill about 16,000 Georgians per year.  
- How does Georgia rank in the U.S.?
  - 2nd highest for child obesity
  - 7th highest for infant mortality
  - 6th highest HIV/AIDS diagnosis rate
  - 11th highest TB case rate

Georgia Research Alliance
- This nonprofit in Atlanta is aligned with the Georgia Department of Economic Development.
- GRA partners with major universities to expand their research capacity and fuel the transfer of research-based knowledge to new companies.
- Example: Venture funding through GRA enables Georgia Tech researchers to market and produce microneedles that can deliver medicines safely to the eye.

The Task Force For Global Health
- This Decatur-based nonprofit organization researches gaps in the knowledge and treatment of neglected tropical diseases.

GeoVax
- Founded through a collaboration between the National Institutes of Health and the Centers for Disease Control and Prevention, Atlanta-based scientists at GeoVax are currently testing an HIV/AIDS vaccine that has passed Phase II clinical trials.

Centers for Disease Control and Prevention
- As the first in the world to identify the H1N1 flu virus, the CDC worked rapidly with global partners at the onset of the pandemic to limit its spread.

NeurOp
- NeurOp is funded by NIH to research treatments and prevention methods for central nervous system conditions such as traumatic brain injury, depression, stroke and pain.

Morehouse School of Medicine
- Funded by NIH, the Prevention Research Center is working to increase nationwide colorectal cancer screenings.
- The neuroscience institute uses NIH funding to conduct research on topics including stroke, circadian rhythms, sleep disorders, epilepsy and the visual system.

Georgia Tech
- Georgia Tech is a part of an NIH-funded consortium researching malaria diagnostics, drugs, vaccines and parasites.
- Researchers at the Nanomedicine Center study correction technologies for disorders like sickle cell anemia.

Emory University
- Emory’s research has contributed to 57 startup companies and brought more than $806 million to Georgia from biomedical licensing revenues.
- Researchers receive NIH funds to study hormone treatment for traumatic brain injury.
- NIH sponsors Emory to conduct vaccine clinical trials for infectious diseases.

University of Georgia
- NIH is sponsoring a study using laser technology to rapidly identify different strains of influenza, such as H1N1, H7N9, H5N1, etc.
- Scientists are researching blood cell formation to better understand and treat anemia.
Why is federally funded biomedical research important to Georgia?

- Supports research studies at university, medical centers and independent research institutes
- Trains new scientists
- Produces medical cures, treatments and preventative measures
- Creates innovative technology
- Tracks and controls outbreaks
- Builds the biosciences industry
- Keeps Georgia competitive

Investing in Georgia’s Future

- According to Georgia BIO, 1 out of every 40 jobs is tied to the core life sciences industry (pharmaceuticals, medical device and biotechnology), R&D, academia or the CDC. ¹
- The medical device industry as well as private research and testing laboratories have had major employment growth (28%) from 2007-2010 as compared to the rest of the U.S. ²
- Combined, life science companies, universities and the CDC have an annual economic impact of $20 billion in Georgia. They support more than 94,000 jobs; of those jobs, more than 33,000 are directly supported by the Georgia research ecosystem. ³
- Georgia bioscience employees’ average salary is more than $80,000. The average salary for a Georgia worker is about $44,000. ²
- In 2011, $441.2 million in NIH funding supported more than 10,000 jobs in Georgia. ³

Sources: Georgia BIO¹; Battelle Industry Development 2012²; UMR³

Public Aspirations for Georgia Leadership

How important is it for Georgia to be a leader in the following enterprises?

- Education: 82% Very important, 16% Somewhat important, 1% Not very important, 0% Not at all important
- Health R&D: 67% Very important, 29% Somewhat important, 3% Not very important, 0% Not at all important
- Manufacturing: 51% Very important, 40% Somewhat important, 8% Not very important, 0% Not at all important
- Defense: 49% Very important, 35% Somewhat important, 13% Not very important, 0% Not at all important

“…”

--Dr. Walter J. Curran Jr., Executive Director of the Winship Cancer Institute at Emory University, The Atlanta Journal-Constitution, March 22, 2013

Source: A Research!America poll of U.S. adults conducted in partnership with Charlton Research Company in May 2011.