The House and Senate subcommittees on Labor, Health and Human Services, Education, and Related Agencies have released funding recommendations for the National Institutes of Health, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality.

At the time of this writing, the House has released and passed funding recommendations at the subcommittee level, which include flat funding for NIH, a deep 11.8% cut to CDC and zeroing-out of the entire AHRQ budget.

“How can Congress justify the elimination of a critical health agency and severe cuts to other programs under the House Labor-HHS-Education appropriations subcommittee bill?” Research!America President and CEO Mary Woolley said in a statement in response to the recommendations. “We cannot afford to zero out funding for [AHRQ] at a time when it is addressing medical errors that kill more than 100,000 people a year and accelerating patient access to the best medical practices. We cannot afford to slash the [CDC] budget when it barely has enough funds as it is to protect Americans against pandemics, bioterrorism, and outbreaks of dangerous and deadly infectious diseases. Unfortunately, House Funding Recommendation Eliminates AHRQ, Slashes CDC

An ad campaign to promote Your Candidates – Your Health, Research!America’s signature voter education initiative, has begun appearing in Politico, the Capitol Hill publication.

The campaign serves to underscore the urgency of getting candidates for the House, Senate and presidency on the record to explain their views on issues related to research to improve health.

The ad, featuring a father and his daughter, who holds a flag, urges candidates to share their views on www.yourcandidatesyourhealth.org. The ad also features a memorable quote from Research!America’s chair emeritus, The Honorable Paul G. Rogers: “Without research, there is no hope.”

The full-color ad appeared once in July and will appear again in the fall, closer to the general election.

And if you haven’t asked your candidates to participate, please visit the website and do so. As Research!America’s president and CEO, Mary Woolley, has often said, research won’t be a priority after the election if stakeholders don’t make it a priority before the election.

In the area of medical and health research, compared to other countries, do you think the U.S. is first in the world, is it ahead of other leading countries, behind other leading countries or about the same as other leading countries?

SOURCE: A RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS IN MARCH 2012.

Less Than A Quarter Believe U.S. is World Leader in Medical Research

- First in the world: 23%
- Ahead of other leading countries: 45%
- Behind other leading countries: 20%
- Not sure: 12%
WebMD may be best known for its eponymous website, which focuses on consumer health information, but that’s only one part of the corporation. As a whole, WebMD has 1,400 employees and employs operations in private health portals, news for medical professionals and publications. But WebMD.com remains a go-to source not only for the public but for scientists and researchers as well.

From idea to publication, all content on WebMD.com is physician-reviewed—and written by veteran health journalists; the process helps ensure scientific accuracy while maintaining readability for a non-scientific audience. Even deciding what’s newsworthy has its own process.

“We want to make sure the information we’re putting out there is actually useful and people can take action,” WebMD’s chief medical editor, Michael W. Smith, MD, said.

And the website isn’t just for the public. Smith said scientists can benefit from WebMD because the level of reporting goes into some detail about the parameters and potential problems of a given study; scientists can therefore make a quick decision on whether a study is credible.

As a brand, WebMD is reputable and familiar; it has often been listed among comScore’s top 50 U.S. web properties. That standing allows it to help advance public health by partnering with the federal government on various initiatives; through Medscape, it does likewise with health care providers. Matt Holland, WebMD’s executive director of government services, said that in the cases of implementing the Affordable Care Act and electronic health records, the company helped educate both professionals and the public through its multiple platforms.

A membership with Research!America aligns with one of WebMD’s goals: helping the public realize that research matters.

“One of the areas we do definitely address when we’re dealing with condition-specific information—in addition to educating about the condition—is the importance of research,” Smith said. “Not only talking about the research that’s been done on that condition but also educating about the awareness of clinical trials and the benefit of medical research.”

For more, visit www.webmd.com.
Media

Senate Bill Falls Short in Research Funding for FY13
Research!America’s chair, former Congressman John E. Porter, expressed both his gratification and disappointment in the slight increase to the National Institutes of Health budget in the FY13 Senate Labor-HHS-Education appropriations bill. The statement was printed June 12 in the Nature News Blog. That same outlet, along with the Think Progress blog, also quoted Research!America President and CEO Mary Woolley in a statement reacting to the House LHHS Appropriations Subcommittee’s funding recommendation for FY13.

Impact of Sequestration Gains Traction in Media
Research!America’s report, “Sequestration: Health Research at the Breaking Point,” has increased awareness of the impact of the automatic spending cuts to federal health agencies among policy makers and the media. “At the beginning of the year, a lot of people felt this [sequestration] could never happen,” Mary Woolley said in CEO Update. “But now, it’s a wake-up call, like a heavily caffeinated coffee.” In June, The Boston Globe cited Research!America’s report in an article on Rep. Ed Markey (D-MA) asking Department of Health and Human Services Secretary Kathleen Sebelius for details on the impact of sequestration to research. The Globe quoted the sequestration report in a follow-up article on Markey’s letter and the response from HHS. Eleanor “Ellie” Dehoney, Research!America’s vice president of policy and programs, also described the impact of automatic spending cuts to Genetic Engineering & Biotechnology News.

Health Reform Law Supports Research
A day after most of the Affordable Care Act was upheld by the Supreme Court, Mary Woolley was quoted in The Scientist, saying it is now time to talk about research and innovation as a major driver of improvements in health care. The article highlighted provisions of the law that support biomedical research.

Research Advocates Blanket Country with Op-Eds and Letters to the Editor
In an op-ed published in several Montana newspapers, Dave Poulsen, PhD, a research associate professor at the University of Montana and The Montana Neuroscience Institute, and Rob Bargatze, PhD, chief science officer at LigoCyte Pharmaceuticals, made a plea for Congress and the White House to work together to ensure that funding for medical research is a top national priority. In response, the Billings Gazette published a letter to the editor from Mary Woolley about the importance of knowing where candidates stand on research to improve health. Woolley also responded to a USA Today article titled, “Mitt Romney’s secret weapon: Wife Ann, and her lesson of MS,” writing, “MS research, along with research for other serious illnesses, is not being funded at a level consistent with scientific opportunity.”

Research!America Ads Get Press
Research!America’s advertisements promoting Your Candidates–Your Health and global health R&D have appeared in Politico and in rail stations in the Washington (DC) Metropolitan Area Transit Authority recently. To date, Politico Pro, Kaiser Daily Health Policy Report, FDA Week and the National Journal’s Influence Alley mentioned the Research!America “Nice Save” global health ads. 

President’s MESSAGE
Research!America Chair John Porter has been driving home the message that this is the “most important election of my lifetime.” Many would agree; it isn’t often the case that there is such an enormous gulf in the electorate between those who espouse a strong role for government and those who believe that the government should have less of a role in all but a few areas, defense being number one on the essential list. Where does our issue fit in? What can we do to assure it is also essential?

Research and innovation have historically enjoyed bipartisan support, but that is difficult to achieve in the current political climate. Our issue is simply not talked of, with the result that it has slipped so far down the priority list of those running for office that few even mention it. Some say they don’t have time to respond to our voter education questionnaire—an indication, if there ever was one, that research for health is not a priority for the candidate.

When you consider that each of us is a lifelong beneficiary of medical progress and a taxpayer whose priorities should matter, “I don’t have time” is a disturbing answer. What will each of us, individually, stand for and take action on, when it comes to this election? The last—very last—thing any of us can do is to let “I don’t have time” to respond to questions about research for health stand as a response. Please track down the candidates in your state and district and ask them to respond to our voter education questionnaire at YourCandidatesYourHealth.org. If the candidates don’t care now, what are the chances they will act to save health and medical research later?

Mary Woolley

The RESEARCH ADVOCATE 3
the subcommittee started with a funding level that almost assured the measure released today.” (Click here to view the statement in its entirety.)

In June, the Senate Appropriations Committee recommended increasing the NIH budget by $100 million, flat-funding CDC and slightly cutting the AHRQ budget.

Senate leadership has indicated that no funding bills will be passed until after the elections, well after the start of the fiscal year on October 1. On July 31, Speaker John Boehner (R-OH) and Senate Majority Leader Harry Reid (D-NV) announced their agreement to pass a six-month continuing resolution (C.R.) in September. Both houses will vote on the C.R. when they return from their August recess.

The prospect of sequestration, or across-the-board budget cuts, continues to loom. Without congressional agreement, cuts of at least 7.8% affecting all research agencies would occur on January 2, 2013. Research!America has been vocal in opposing these cuts and has been working to raise awareness regarding their counterproductive impact.

Sequestration is one of several dramatic budget changes scheduled to occur around the same time, including expiration of the Bush-era tax cuts and the payroll tax cut, as well as the end of extended unemployment benefits for Americans who still lack jobs in our sputtering economy. Ultimately, policy makers are likely to devise a package that addresses most or all of these issues, but it will be a steep uphill battle. In the interim, Congress may act to delay the start date of the sequester and other policy changes, pushing them back by weeks or months to allow for more time for a deal to be reached.

In the midst of this fiscal turmoil, the fate of federally funded research depends, in part, on you. If Congress does not hear from the Americans they represent that research is a lifeline, not a luxury, then the budget knife will fall on NIH and the other research agencies. Budget cuts will be made. We need to make sure they are not made at the expense of medical progress. It is simply too big a price to pay.

** 2013 FEDERAL RESEARCH BUDGET  

<table>
<thead>
<tr>
<th>Agency</th>
<th>FY13 President’s Request</th>
<th>FY13 House</th>
<th>FY13 Senate</th>
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<td>National Institutes of Health</td>
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<td>Agency for Healthcare Research and Quality**</td>
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<td>$0</td>
<td>$0.36 billion</td>
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</tbody>
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* CDC core budget. The House bill terminated funding for the Prevention and Public Health Fund.  
** Excludes funding from transfers.

Note: At the time of this writing, funding levels have not gone to a floor vote for NIH, CDC, FDA and AHRQ. NSF funding levels have been approved by the House but have not been voted on by the Senate.
Research!America Ads Bring Awareness to Global Health R&D

A four-part ad series from Research!America showcases the sometimes-unexpected benefits of investing in global health R&D.

The series, titled “Nice Save—American Ingenuity Saves Lives,” illustrates how certain therapies and devices found new life in the treatment of diseases for which they were not initially developed. Each of the ads uses sports imagery at dramatic moments to further illustrate the idea: a baseball player making a diving catch, a volleyball player with a dramatic spike, and goalkeepers in soccer and ice hockey preventing goals.

Drugs and devices featured in the series, among others, include products from Temptime Corporation, which were originally meant to indicate food freshness but now warn against dangerous temperatures for vaccines, and the GeneXpert System, which was designed to detect anthrax in mail but was later adapted to test for TB infections.

The fundamental goal of the ads is to demonstrate that R&D cannot be strictly categorized as global or domestic; by propelling medical science forward, U.S. funding for R&D and policies that promote philanthropic and private-sector medical discovery serve the best interests of us all. The ads ran in Politico, the Capitol Hill newspaper, in late June. In July, the ads were displayed in rail cars on the Washington Metropolitan Area Transit Authority (in the DC region, the agency is better known as Metro). The ads were featured on Metro’s red line, which runs in a “U” shape from parts of suburban Maryland to downtown Washington. One of the red line’s stations serves the National Institutes of Health.

To see the ads, visit our Action Alert: http://capwiz.com/ram/issues/alert/?alertid=61480736&PROCESS=Take+Action.

NIH to Expand Its Undiagnosed Diseases Program

The National Institutes of Health announced that it will expand its Undiagnosed Diseases Program to as many as six universities.

Currently, the program is housed solely on the NIH campus in Bethesda, MD, and sees 150 patients per year, according to ScienceInsider. In July 2011, the program announced it would temporarily stop accepting new patients to deal with a backlog of cases.

At the new sites, researchers will be trained in the program’s methods and see as many as 50 patients per year. Including those seen in Bethesda, that could mean as many as 450 patients are seen per year.

The expansion is being paid for with money from the NIH’s Common Fund.

Kennedy to Appear at Udall Awards Dinner

The Honorable Patrick Kennedy, a Research!America Board member, will be the special program guest at the 2012 Morris K. Udall Awards Dinner. The dinner is hosted by the Parkinson’s Action Network, a Research!America member.

Kennedy will be interviewed by National Public Radio host Diane Rehm. Rehm, along with her husband, John, and Roll Call senior editor Morton Kondracke, are dinner co-chairs.

The dinner, which will be held October 3 in Washington, DC, is named for The Honorable Morris “Mo” Udall, a noted champion for Parkinson’s in Congress.

Mary Woolley and NHGRI Director

Mary Woolley Presents at NHGRI

Research!America President and CEO Mary Woolley was a guest speaker at the National Human Genome Research Institute at the National Institutes of Health. Woolley’s speech was part of NHGRI’s annual Town Hall; it focused on the return on investment in medical research as well as the current state of government funding and public attitudes toward research, research funding and U.S. leadership in science.
Abbott, Bristol-Myers Squibb, GlaxoSmithKline, Janssen Pharmaceuticals and Sanofi joined the National Institute of Health’s Discovering New Therapeutic Uses for Existing Molecules program, which uses old compounds to create new therapies.

The National Science Board is accepting nominations for the 2013 Vannevar Bush Award.

David M. Murray, PhD, was appointed associate director for disease prevention and director of the Office of Disease Prevention at NIH.

A new report by amfAR found that slashing $689 million from global health programs is equivalent to only 0.63% of the required deficit reduction for FY13—but losing that amount would be devastating to efforts to alleviate disease across the globe.

Those cuts could result in:
- HIV/AIDS treatment for 273,000 fewer people, potentially resulting in 62,000 more deaths.
- Malaria treatment for 3.7 million fewer people, potentially resulting in nearly 6,000 more deaths.
- TB treatment for 65,000 fewer people, potentially resulting in 8,000 more deaths.
- And reduced funding for the GAVI Alliance, potentially resulting in 13,000 more deaths due to diphtheria, tetanus, pertussis, hib and hepatitis B.

Despite the savings, the report states, the cuts will “adversely affect the lives of millions of men, women and children worldwide, resulting in substantial human suffering and squandering of opportunities to build on successes in U.S. global health programming.”

Download the full report at www.amfar.org/uploadedFiles/amfarorg/In_The_Community/SequestrationJuly2012.pdf. amfAR is a Research!America member.

Majority: Medical Research Should be Exempt from Across-the-Board Cuts

Government spending on medical and health research saves lives, creates jobs and fuels innovation and should be exempt from across-the-board cuts 54%

Funding for health research is adequate and the country has other priorities now, including the deficit 34%

Not sure 12%

SOURCE: A RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS IN MARCH 2012.
The International AIDS Conference took place July 22 through July 27 in Washington DC, convening more than 20,000 delegates from nearly 200 countries. It is the first time in 22 years that the conference has been held in the United States. This year’s theme—“Turning the Tide Together”—showcased exciting new breakthroughs in global health R&D that have brought us closer than ever to achieving an AIDS-free generation. Panelists discussed the power of collaboration, country commitments, AIDS policy implications on worldwide health, resource tracking, and the role of faith-based groups, the private sector, activists and researchers to help eliminate AIDS. In a session examining the science of HIV and the road ahead, National Institutes of Health Director Francis Collins, MD, PhD moderated a high-level panel addressing how we can turn science into policy: We must use the economic argument (and religious or moral-based, when appropriate) to convince politicians that not addressing this disease to the fullest of our ability costs us money and causes a loss of workforce in many countries.

Speakers included Secretary of State Hillary Clinton, Secretary of Health and Human Services Kathleen Sebelius, National Institute of Health Director Anthony Fauci, MD, philanthropist Bill Gates, and many others. To learn more about AIDS2012, visit www.aids2012.org.

Americans Believe Science, Math Education Will Impact Future of U.S.

On a scale of 1 to 5, please rate science and math education relative to how seriously you believe each will impact the future of the United States.

Not yet a member? Join Research!America today at www.researchamerica.org/supportourwork

Research!America Releases Fact Sheet on Hip Fractures and Osteoporosis

The latest in Research!America’s fact sheet series, “Investment in Research Saves Lives and Money,” focuses on the medical advances—and resulting cost savings—of research in hip fractures and osteoporosis.

The fact sheet (see insert) was produced with support from the American Society for Bone and Mineral Research, a Research!America member.

Besides the increase in lifespan due to advances in this area of research, savings are achieved as well. In one example, Kaiser Permanente’s Healthy Bones model of care was shown to reduce subsequent hip fractures by 38%. If implemented nationally, the program could result in nearly $3 billion in savings.
Congress is Weighing Research Cuts; Contact Your Representatives NOW

Congress is on the verge of making major decisions on funding for medical research. There is extraordinary political pressure to cut funding, and it’s important that you and all advocates step up now. Contact your representatives and ask them to make funding increases for medical research a top priority.

Boosting our investment in research is critical to improving the health of Americans while powering our economy. Be sure to share this action alert on Facebook and Twitter, and email it to your networks! Americans need to speak up for life-saving medical research. Time is of the essence!

Visit US ON THE WEB

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- Watch our YouTube channel: www.youtube.com/researchamerica
- Visit our blog: www.researchamerica.org/blog
Investment in research saves lives and money

facts about:

Hip Fractures & Osteoporosis

“"If you think research is expensive, try disease.”
— Mary Lasker 1901–1994

The Cost:

- Osteoporosis was one of the 10 most costly chronic conditions to Medicare in 2010.*
- The number of osteoporotic fractures annually currently exceeds the incidence of heart attack, stroke and breast cancer combined.**
- Fractures from osteoporosis and low bone mass cost $19 billion a year in the U.S. This is expected to rise to $25.3 billion per year by 2025 as the elderly population nearly doubles.***


Today:

- Osteoporosis makes bones porous, affects more than 40 million Americans who either already have osteoporosis or are at high risk due to low bone mass, and increases the risk of sustaining a hip or other serious fracture.*
- Each year, more than 281,000 older adults in the U.S. suffer hip fractures. More than 20% of hip fracture patients die within a year of their injury.**
- Among women age 67 or older who had an osteoporosis-related fracture, only 20% had either a bone density test or a prescription for a drug to treat or prevent osteoporosis in the six months after the fracture.***


HOW RESEARCH SAVES LIVES:

- Research funded by the NIH has shown that osteoporosis can be treated to prevent hip and other fractures. Current research is focused on exploring the roles of genetics, hormones, calcium, vitamin D, drugs and exercise on bone mass to improve diagnosis and prevent the development of osteoporosis.*

*SOURCE: NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES, NIH

- Medical advances such as bisphosphonates and increased bone density screening are having a positive effect on bone health. Between 1995 and 2005, the age-adjusted hospitalization rate for hip fractures among older Americans decreased. For women aged 65 years or more, the rate decreased 24.5%. For men in the same age range, the rate decreased 19.2%.**

*SOURCE: NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES, NIH

HOW RESEARCH SAVES MONEY:

- Inpatient hip fracture care costs $26,000 per episode. Few patients regain their former level of independence after hip fractures, with a lifetime cost estimated at $81,000 for skilled and long-term nursing care. By reducing the incidence of hip fracture, research is helping to address these staggering costs.***


NAME: BOB WHITE
AGE: 64
DISEASE: OSTEOPOROSIS

Survivor:

Bob White is a healthy guy by most standards. But around the holidays in 2010, Bob developed a really bad cough. The cough was so severe that it caused a fracture in one of the vertebrae in his back. Knowing his mother had osteoporosis, he decided to get a bone density test. The test revealed Bob has osteoporosis too.

Bob began taking a bisphosphonate to increase his bone density. He and his wife started walking several miles every day, which improved the lingering pain in his hips and back from the fractured vertebrae, and they began making a concerted effort to eat nutrient-rich foods and supplement that with calcium and vitamin D.

Bob’s mother fractured her hip when she was 90 years old and died 11 days after hip surgery. Until a few months prior to the fracture, she had been able to maintain a high degree of independence. Bob looked at his own condition with new eyes, wondering if this is his future as well. He and his wife began attending a class on building bone strength and greater balance to prevent bone loss and falls.

Bob shared his story to remind others of the importance of getting tested for osteoporosis and caring for their health and bones. The best way to fight osteoporosis and hip fractures is to invest in research for new therapies and preventive strategies, which will prevent hip fractures and help patients like Bob live healthier, more productive lives.
Hope for the Future:

- By studying patients with high bone mass and investigating how bone cells communicate with one another, researchers have discovered new pathways of bone formation that hold promise for the development of new therapies for osteoporosis. Several anti-osteoporotic compounds based on this research are currently in clinical trials.*

- With ongoing research, scientists hope that osteoporosis will come to be considered a curable disease. Research has enhanced our knowledge about how to maintain a healthy skeleton throughout life and has led to progress in understanding the causes, diagnosis, treatment and prevention of osteoporosis. Every research advance brings us closer to eliminating the pain, suffering and cost caused by this disease.**

**Source: National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH

The Bottom Line:

Twenty years ago, physicians had very few treatment options for osteoporosis. Today, many high quality clinical trials have established that bisphosphonates prevent most types of serious fractures and thus are of benefit to millions of patients in the U.S. and worldwide. These drugs are helping strengthen bones and decrease the risk of hip fracture, but there is still a need for better drugs and increased screening for at-risk populations.