Take Action Now

Encourage Congress to pass an FY17 budget.

Learn more on page 8.

Joe Biden and Kathy Bates Urge Advocates to Redouble Efforts for Research at 21st Annual Advocacy Awards Dinner

Honorees at Research!America’s 21st Annual Advocacy Awards Dinner on Wednesday, March 15 in Washington, D.C., exemplify the steadfast commitment of advocates for research in defeating disease and strengthening our nation’s preeminence in science and innovation.

Joe Biden, 47th Vice President of the United States, was presented with the Gordon and Llura Gund Leadership Award for leading the White House Cancer Moonshot Taskforce and The Biden Foundation’s cancer initiative. In his remarks, Biden said now is the time to redouble our efforts to fight cancer. “We can make sure many more chronic diseases don’t cost you your life, but only if we break down barriers. I see the day a patient is given the right therapy the first time when they are diagnosed. I see the day when prevention is more effective, and where care is personalized and more effective with less side effects.”

Anthony S. Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases, received the Legacy Award for his tireless work to prevent, diagnose and treat infectious and immune-mediated diseases. “I’m entirely grateful to have been put into this position and to have been witness to and to have played a relatively small part of this extraordinary story of biomedical research,” he said in his acceptance speech.

Advocates Discuss Need for Funding at Research!America’s Annual Meeting

Medical research not only benefits the health of individuals, it benefits communities and the local economy, said Rep. David McKinley (R-WV-01) during Research!America’s 28th Annual Meeting of Members on Wednesday, March 15 in Washington, D.C. “We know that the NIH supports over 400,000 jobs across America. Every year NIH writes grants for [scientists and institutions across the country]. That’s significant.”

In her remarks, award-winning actress and Lymphatic Education & Research Network (LE&RN) spokesperson Kathy Bates stressed the importance of research in tackling lymphedema, a chronic and often-misdiagnosed disease of the lymphatic system that causes painful and disfiguring swelling throughout the body. She also called on medical schools to spend more time teaching students about the lymphatic system.

Lymphedema, which affects 10 million Americans – more than MS, muscular dystrophy, ALS, Parkinson’s and AIDS combined – can put sufferers at risk for other conditions like the bacterial skin infection cellulitis. Although there’s currently no cure for lymphedema, treatment includes wrapping the affected areas in compression garments. Bates urged Congress to pass a bill that would help cover the cost of those garments.
President Trump’s so-called “skinny budget” for the 2018 fiscal year proposes major cuts to our nation’s health research agencies, among other program cuts designed to shift dollars to defense. Another wave of proposed cuts to the still-unresolved fiscal 2017 budget has also been released. “Proposed” is a key word here, since it is the Congress, not the President, that determines spending. (More often than not, over the last three decades, presidents have proposed cuts in science budgets, only to see the Congress allocate more support to science.) All signals are that this President’s budget is not being warmly received on Capitol Hill, but that doesn’t mean we can afford to dismiss it. The proposed cuts are large and the accompanying language begs the question, “why should the government pay for research?”

Our answer is clear: the public should pay because research is a public good. It is like defense in that regard. By my math, the U.S. spent roughly $645.3 billion to defend our nation last year, and about a fraction as much ($33.5 billion) to defend our health. If you agree that research is a public good, this is the time to call your elected representatives. Say ‘no’ to the Trump budget cuts for science! And say ‘yes’ to the March for Science on April 22.
Federal Policy Update

There is still a strong chance that Congress will pass an FY17 omnibus bill rather than resort to continued flat-funding under a year-long continuing resolution (CR). We understand that the pending FY17 omnibus includes a $2 billion increase for NIH, as well as increases for CDC, NSF and FDA.

As for FY18, President Trump released his “skinny budget” blueprint which proposes cuts to NIH and other research agencies. It also recommends elimination of the Fogarty International Center at NIH, and AHRQ would be incorporated into the Institutes. Additionally, the proposal would reduce the federal government’s financial stake in FDA and cut the budget line for “Other Agencies” -- which includes NSF -- by nearly 10%.

The opioid crisis remains a major focus for both the White House and Congress. Recently, the House Appropriations Committee held a hearing regarding the federal response to the crisis. The President has established a task force charged with accelerating our nation’s offensive against this public health threat.

Scott Gottlieb, M.D., has been nominated to serve as FDA Commissioner. The Senate HELP Committee held a hearing on Dr. Gottlieb’s nomination on April 5. The Committee is expected to vote on Dr. Gottlieb’s nomination during the last week in April or in early May.

The House and Senate have convened several FDA hearings to consider the FDA user fee reauthorization bills. Members of Congress are working to pass these bills expeditiously; FDA estimates that between 30% and 70% of employees could receive Reduction in Force (RIF) notices if the bills are not signed into law by July 31.
Precision Medicine in Action

The idea of manipulating a patient’s immune response to target cancer dates back a century, but only recently has the technology to apply it has become available, said Glenn Dranoff, M.D., global head of exploratory immunology, Novartis, during a discussion hosted by Johns Hopkins Medicine on March 8 in Washington, D.C. Panelists discussed precision medicine as it relates to cost, communication, research, and health care delivery.

Dranoff pointed to immunotherapy to treat melanoma, which can achieve 10 years survival through as little as four treatments, as an example of how far precision medicine research has come.

Antony Rosen, M.D., vice dean for research, Johns Hopkins Medicine, said there are challenges to advancing precision medicine with insufficient funding, noting a 20% decline in the National Institutes of Health (NIH) budget over the past 15 years. With President Trump’s proposed deep cuts to NIH funding for both FY17 and FY18, those challenges could be amplified, he added.

“We are concerned about the prospect of budget cuts at NIH because if you don’t have the NIH providing seed corn for this research, then you don’t reap the benefits,” said Margaret Anderson, executive director of FasterCures. “The urgency of this work as it applies to real life patients cannot be underscored enough.”

Science, Not Silence

On Saturday, April 22, the March for Science will take place in more than 400 cities across the globe to celebrate the many scientific advances that have improved the health and well-being of people worldwide. Research!America will be on the ground participating in the Washington, D.C., event, and some of the satellite marches in Los Angeles, CA, Oklahoma City, OK and Salt Lake City, UT.

“The March for Science event in Washington, D.C., along with similar activities across the country and around the world will provide opportunities for scientists from all disciplines to elevate their level of civic engagement and amplify how science serves society, accelerating medical progress, saving lives and creating a better world for the next generation,” said Research!America President and CEO, Mary Woolley.

Research!America – along with dozens of other organizations, including many of our members – is a March for Science partner and continues to play an active role in spreading the word about the importance of using evidence-based science to shape policy decisions that affect us all. We have written letters in publications across the country calling on those who care about the health and prosperity of America to get engaged and participate in the March for Science. We urge you to do the same.

Publisher Mary Ann Liebert is distributing GoGreen Shoelaces for Science™ in support of the March for Science. Request laces for your colleagues, faculty and students by emailing GoGreen@liebertpub.com and #LaceUpforScience!


Federal Research Budget

<table>
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<tr>
<th>AGENCY</th>
<th>FY15</th>
<th>FY16</th>
<th>PRESIDENT’S FY17 REQUEST</th>
<th>RESEARCH!AMERICA’S FY17 ASKS</th>
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<td>8.9%</td>
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* indicates that program level is reported in this chart
** indicates that budget authority is reported in this chart
Advocacy Awards Dinner
Research!America’s 2017 Advocacy Awards Dinner, which honored former Vice President Joe Biden, Kathy Bates and leaders in medical and health advocacy, was highlighted in The Hill, The Washington Post, The Huffington Post, Roll Call, and WJLA-TV (Washington, D.C.) as well as in numerous broadcast and online news sites.

New Board Leaders and Directors

President Trump’s Budget Proposal
Research!America Chair Emeritus The Hon. John E. Porter’s comments about President Trump’s proposed budget cuts to research were included in an article in The Cancer Letter. Mr. Porter and Research!America board member Susan M. Fitzpatrick Ph.D., president of the James S. McDonnell Foundation, were quoted in the Chronicle of Higher Education about the impact of potential budget cuts to academic researchers.

Letters to the Editor
Woolley’s letters to the editor calling for stronger investments in research and public health are published in The Wisconsin State Journal, The Tennessean, and The Mercury News (San Jose, CA).

Investments in Research
Data from Research!America’s Investment Report was included in a Science magazine article about basic research funding in the U.S.

Public Investment in Universities
Shepherd University President and Research!America board member Mary Hendrix, Ph.D., described the return of public investments in university programs in an op-ed published in The Journal newspaper.

IN BRIEF
• The National Academy of Sciences is seeking nominations for two awards that support the formation and development of collaborative science communication researcher-practitioner partnerships. http://bit.ly/2odw3QL
• American Heart Association President Nancy Brown, Research!America board member, discussed the My Research Legacy Initiative in a Huffington Post article. http://huff.to/2odxT4l
• The Coalition for Clinical Trials Awareness is hosting a policy roundtable on May 3 to discuss how the federal government can increase awareness of clinical trials. http://bit.ly/2oQG18F
Policy Session at the AACR Annual Meeting Highlights Importance of Research

Proposed budget cuts to medical research have raised concerns among cancer research advocates who participated in the American Association of Cancer Research (AACR) Annual Meeting on April 3. The policy session’s keynote speaker Joe Biden, 47th Vice President of the United States, said it’s time to double down on research, not undercut progress. “We can fundamentally change the prospects and promise of life for tens of millions of people around the world,” he said.

The session titled The Beau Biden Cancer Moonshot: Progress and Promise included leaders from government, academia, industry and patient advocacy groups for a discussion about progress with the initiative.

Panelist Rep. Kevin Yoder (R-KS-03) said, “Cancer knows no political party and knows no region. It affects every street and every cul-de-sac in America and therefore it affects every member of Congress and their constituents.” He added that it is helpful for policymakers to hear personal stories from patient groups, what they went through and why research matters. For scientists, Yoder said, it is important to hear about the exciting research being conducted and explain what is holding their work back.

Other panelists included Douglas Lowy, M.D., acting director, National Cancer Institute; Michael Caligiuri, M.D., AACR president-elect; Elizabeth Jaffee, M.D., AACR incoming president-elect; Elaine Chao, Secretary of Transportation; Richard Pazdur, M.D., director, FDA Oncology Center of Excellence; and Fran Drescher, actress and founder of Cancer Schmancer. AACR president Nancy Davidson, M.D., moderated the discussion.

Clinical Research Achievement Awards

Opioid addiction, lung disease, asthma and prostate cancer research are among those being recognized with The Clinical Research Forum’s Top Ten Clinical Research Achievement Awards. The annual competition seeks to identify major advances resulting from the nation’s investment in research to benefit the health and welfare of its citizens. This year’s award ceremony will be held on Tuesday, April 18 at the National Press Club in Washington, D.C.

The awards shine a spotlight on innovative, ground-breaking research from some of our nation’s most prestigious academic institutions and medical centers, including a number of Research!America Alliance Members.

Award recipients are working on new and promising treatments in the following areas: environmental exposures and asthma; treating opioid addiction; lung disease treatment; prostate cancer; rheumatoid arthritis treatment; evaluating hospital performance; atherosclerosis in communities; essential tremor therapy; autoimmune disease therapy; and cesarean section infection prevention. For more information on the award recipients and to RSVP for the ceremony, visit clinicalresearchforum.org.

Are We Ready for a Pandemic?

Threats are no longer limited to weapons of wars; they include widespread disease outbreaks. Panelists at a briefing hosted by the Bipartisan Policy Center (BPC) agree that pandemics pose a major threat to national security.

“Over the last 15 years, the U.S. and the world has faced anthrax, SARS, avian influenza, pandemic influenza, Ebola and Zika,” said Anand Parekh, M.D., chief medical advisor, BPC, at the forum held March 28 in Washington, D.C. “As opposed to other threats, microbes know no borders.”

“We don’t have as clear of a picture of the profound impact” of airborne pathogens, said The Hon. Tom Daschle, former U.S. Senate Majority Leader and BPC cofounder. “We need exclamation points to put forth a sense of urgency and then develop a plan of action.”

The Hon. Judd Gregg referenced Project BioShield, signed into law by President George W. Bush in 2004, as an archetype for pandemic preparedness. The 10-year program allocated $5.6 billion to accelerate research and develop medicines to protect Americans against possible chemical, biological, radiological, or nuclear attack. In 2013, the program was re-authorized through 2018 but its longer-term fate under Trump’s administration is unclear.

“There is no bigger threat to our nation than a biological attack or pandemic flu,” Gregg said. “This is a national security issue and once it’s presented in those terms to this Administration, we will be able to move forward.” View a video of the event at http://bit.ly/2nXg8qk.

Through medical innovation, fatal diseases like HIV are now manageable, chronic conditions, vaccines are preventing childhood illnesses, and immunotherapies are helping to fight cancer, said Pfizer CEO Ian Read during a March 23 luncheon at the National Press Club.

Read said basic research funded by the National Institutes of Health is “a critical step” but noted the pharmaceutical industry’s important role in translating those findings into effective treatments for patients, a sometimes-difficult journey that can take 10 to 15 years.

“Developing a new medicine on average costs $2.6 billion,” Read said. “But less than 12% of the potential medicines that make it to phase 1 clinical trials get approved by the Food and Drug Administration.”

The FDA “has been conditioned by society and Congress to be extremely conservative,” he said, adding the agency should take more risks in the drug development process to help speed things up.

Read said market competition – not additional government regulations or price controls – is key to lowering drug prices. He called for federal tax and trade policies that protect American intellectual property and more investment in manufacturing. Such moves, he said, would boost productivity in the pharmaceutical industry, leading to more drugs on the market and ultimately driving down costs for consumers.
Lung Cancer Alliance (LCA) is the leading and highest rated nonprofit organization dedicated to fighting lung cancer in the nation. Since 1995, we have played a critical role in every major advance – changing how we support, talk about, detect and treat the disease – and turning those impacted into survivors. Using a science-based, strategic approach, our vision is to triple the number of survivors over the next decade. Reaching this goal requires a collaborative effort that links transformative early detection and treatment research, patient and provider services, and changes to health policies that increase research funding and ensure access to high-quality and affordable care.

Since moving to Washington, D.C., over a decade ago, Lung Cancer Alliance’s (LCA) core focus has been to improve outcomes for people diagnosed with lung cancer. Our goals are three-fold: (1) provide personalized support services to address our communities’ unique needs; (2) increase and advance research that fills in gaps and accelerates breakthroughs; (3) devise more coordinated, comprehensive federal plans of action that ensure access to high-quality and affordable care.

With over 220,000 Americans diagnosed with lung cancer each year and close to 160,000 dying from the disease annually as well as a long held stigma that has contributed to a stagnation in survival rates and federal research funding, it is easy to understand why LCA’s health policy work has played such a groundbreaking role.

Lung Cancer Alliance has seen advocacy gains on several fronts to help move the needle in the fight against lung cancer including working to establish the first-ever dedicated federal research funding pipeline for the disease in 2008 through the Congressionally Directed Medical Research Programs (CDMRP) totaling over $120 million to date, enacting legislation that requires NCI to give increased priority to lung cancer research strategies and spearheading the 10-year long effort to secure lung cancer screening as a fully covered preventive service for the millions at high risk for the disease.

“In order to improve survivorship for those impacted by this terrible disease, increased federal funding is crucial for early detection and treatment research to improve our health care delivery system,” said Laurie Fenton Ambrose, president & CEO of LCA. “Life-saving work needs strength in numbers and Research!America gives us valuable support to advance this effort.”

Lung Cancer Alliance will remain the leading advocacy voice for early detection and treatment research at both the regulatory and legislative level to further provide care and support for patients and those at risk.

Whether working with Congress through the Congressional Lung Cancer Caucus or participating in further innovative research initiatives, LCA aims to continue elevating the voice of the lung cancer community by devising policy strategies that sustain federal research funding, support accelerated drug approval processes and more personalized research strategies, prevent barriers to access to high-quality and affordable care and enable collaboration on research endeavors to change the status quo by bringing the most promising treatments to patients sooner. And, lastly, LCA will further efforts, begun over 5 years ago, to expand the responsible implementation of lung cancer screening best practices in communities across the country.

“Research!America’s work helps ‘put gas in our tank’ as it lays the foundation for collaborations with other stakeholder groups who value increased funding for research efforts that impact public health,” said Fenton Ambrose. “Their partnership provides avenues to amplify our collective voices to truly make a difference on issues that matter to all of us.”

**Lung Cancer Alliance**

- **Founded:** 1995
- **Location:** Washington, D.C.
- **Mission:** Saving lives, advancing research and changing health policy by empowering those living with and at risk for lung cancer.

**Federal Support for Basic Research is Critical**

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.

- **Strongly agree:** 34%
- **Somewhat agree:** 16%
- **Somewhat disagree:** 16%
- **Strongly disagree:** 9%
- **Not sure:** 39%

**Source:** A Research!America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2017. Due to rounding, the total may not add to 100%.
Instead of completing work on an updated budget for fiscal year 2017 (FY17) before 2016 ended, Congress passed a temporary stop-gap or continuing resolution (CR) that flat-funds government until April 28, 2017. A draft FY17 “omnibus” spending bill that would direct more funding to NIH-funded research and other key research and public health priorities sits waiting for further congressional action. Members of Congress have indicated they are nearing the finish line on this legislation, which needs to be signed into law by midnight on the 28th or the government will shut down.

Let them know you support their efforts to get the job done! Take action now: http://bit.ly/2nPEIWA.