the promise
of research

2015 ANNUAL REPORT
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LETTER FROM LEADERSHIP

Turning a Moment Into a Movement

Research advocates had plenty to cheer about in 2015 as congressional leaders and the White House stepped up to the plate to re-energize our national commitment to research and innovation. Along with the Campaign for Cures, the ‘moonshot’ initiative to defeat cancer has created a new sense of optimism for medical research and finding solutions to diseases that threaten our health, livelihood and economic security. Half of Americans say they are even willing to pay more in taxes to support cancer research, our national public opinion survey shows, with significant support for a tax hike across the political spectrum. The likelihood of a tax increase aside, enthusiasm for medical progress has been evident on Capitol Hill as champions for research on both sides of the aisle reached agreement on a deal that raised budget caps for defense and discretionary spending, providing substantial funding increases for the federal health agencies.

Indeed, the FY16 omnibus included a $2 billion increase for the National Institutes of Health, the largest increase for the agency in more than a decade, and additional dollars for the Centers for Disease Control and Prevention, the Food and Drug Administration and the National Science Foundation. As a result of intense advocacy on behalf of the Agency for Healthcare Research and Quality (AHRQ), the agency’s budget was spared deep cuts, but given the importance of its work in addressing inefficiencies in our health care system the agency remains sorely underfunded. We will continue to insist that AHRQ is essential to assuring that the groundbreaking discoveries that deepen our understanding of how to treat and prevent complex diseases benefit patients in a safe and efficient manner.

Congress also made significant strides in removing barriers to private sector innovation with a tax extenders package that improves the R&D tax credit and makes it permanent, and also suspending the medical device tax for two years. Those actions, along with the funding boost, enable medical innovation to move at a faster pace, bringing state-of-the-art medical devices and cures to patients. The research continuum thrives on both public and private sector investments aimed at advancing treatments and disease prevention strategies. Partnerships in precision medicine, cancer, Alzheimer’s research and other ambitious projects are critical to leveraging big data, resources and collaborating brainpower to turn the promise of research into a movement that can be sustained over time.

Research!America continues to keep our finger on the pulse of the latest Capitol Hill developments, public sentiment, coalition activities, media coverage and social media conversations. We will work closely with congressional leaders to bring medical innovation bills across the finish line, educate policymakers about the critical role of social and behavioral research in addressing major health challenges, and advocate to lift the ban on gun violence prevention research under the auspices of the Centers for Disease Control and Prevention.

We will continue to monitor and comment on issues that impact the work of our member organizations. During the election season, our national voter education initiative, Campaign for Cures: Vote for Medical Progress, aims to inform all candidates running for national office that research for health is a priority for voters and must be given the attention it deserves on the campaign trail. If we hope to win the battle against current and emerging health threats, policymakers, candidates and the public must hear from research advocates. This we can do. Let’s make it happen!

The Honorable
John Edward Porter
Chair

Mary Woolley
President and CEO

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The value of medical research innovation is extensive and transformative, providing broad benefits to public health, security, and the economy. Together with our more than 360 alliance member organizations, Research!America successfully advocated for crucial funding and pro-innovation policy changes. We helped secure meaningful funding increases for research agencies, suspended the medical device tax, protected the Agency for Healthcare Research and Quality (AHRQ) from drastic budget cuts or termination, and established a permanent and enhanced R&D tax credit. We also played an active role in advancing the 21st Century Cures Act (H.R. 6), groundbreaking bipartisan legislation to bolster the discovery, development, and delivery pipeline. H.R. 6 passed the House with overwhelming bipartisan support. During 2015, Research!America took part in 145 meetings with Congressional offices, and our members joined us on 16 action alerts to Congress. When Research!America spearheaded a letter to the Committee on Energy and Commerce in support of mandatory funding in H.R. 6, more than 180 organizations signed on. The House-passed bill included a five-year Innovation Fund of $8.75 billion for NIH and $550 million for FDA. We sent 25 other letters and statements to Congress and/or the President in 2015 on topics such as eliminating sequestration, repealing the device tax, and the Next Generation Researchers Act. We also launched a new project to explore evolving public perceptions of medical innovation and identify messaging that captures its multi-faceted individual and societal benefits.

In preparation for the 2016 presidential and congressional elections, Research!America launched Campaign for Cures: Vote for Medical Progress!, a national voter education initiative aimed at ensuring the urgent need for faster medical progress is part of the national conversation during the election season. Research!America is committed to ensuring 2016 brings more action to help our nation realize the unprecedented potential of public and private sector funded medical innovation. If our nation makes medical progress a top priority, we can find solutions to what ails us.

Advocacy Overview

How important is investing in research to job creation, technological breakthroughs and economic growth?

Benefits of Investments in Research

Policy and Advocacy Outreach

We published 22 fact sheets highlighting the multifaceted benefits of medical progress. New fact sheets in 2015 covered health issues such as amyotrophic lateral sclerosis (ALS), rare diseases and eating disorders. Research!America also collaborated with partners and subject matter experts on a special fact sheet series on oral health, highlighting the role oral health plays in systemic health, and the importance of continued research in this field.

To strengthen advocacy in support of federal funding for health services and research (HSR), Research!America hosted an AHRQ webinar to highlight the agency’s accomplishments and discuss the crucial role HSR plays in our health care system.

In 2015, Research!America took part in 145 congressional meetings, issued and sent 26 letters and statements, created 22 fact sheets and spoke at 42 events.
Scientists should be able to inform policymakers about the implications of science, clearly explain research to media and tell their grandmothers the importance of the latest scientific breakthrough, according to a participant at the “Connecting the Dots: Effectively Communicating Science to Non-Scientists” two-day workshop co-hosted by Research!America and George Washington University (GWU) in April. Scientists and communicators from research institutions, government agencies, scientific societies and patient groups across the country and abroad participated in interactive sessions on ways to improve communication with the public, media, donors, and other key decision makers.

The workshop included mock interviews with former CNN White House correspondent and anchor Robin Roberts, anchor and Washington Bureau Chief Frank Sesno, director of GWU’s School of Media and Public Affairs, break out sessions, and lively group discussions about generating compelling stories to connect with non-scientists. “A workshop of this sort should be incorporated into every scientific curriculum,” said participant Debra Cooper, Ph.D., a CCST Science Policy Fellow, California Legislature, Senate Office of Research.

The sessions were led by an esteemed group of experts with backgrounds in science, communication and media. Research!America board members, Jay Gershen, D.D.S., Ph.D., president, Northeast Ohio Medical University; Mary Hendrie, Ph.D., president and scientific director at FasterCures; David Van Andel, director of the National Cancer Institute’s Basic Research Program; Van Andel Institute has become a major contributor to science with the recruitment of top scientists and funding support and Vande Woude is among the pioneers who laid the foundation for the understanding of the molecular basis of cancer.

Michael Milken, founder of the Milken Institute and FasterCures, for leading a range of initiatives for more than four decades that have supported public health, re-envisioned education, expanded access to capital, and accelerated medical research.

Raymond and Beverly Sackler Award for Sustained National Leadership: Kenneth Olden, Ph.D., director of the National Center for Environmental Assessment, U.S. EPA, for championing community-based participatory research in the U.S. and his contributions to cancer research.

Geoffrey Beene Builders of Science Award: David Van Andel, Chairman and CEO of Van Andel Institute in Grand Rapids, and George Vande Woude, Ph.D., director of the National Cancer Institute’s Basic Research Program. Van Andel Institute has become a major contributor to science with the recruitment of top scientists and funding support and Vande Woude is among the pioneers who laid the foundation for the understanding of the molecular basis of cancer.

Paul G. Rogers Distinguished Organization Advocacy Award: The Society for Neuroscience for advocating for robust funding to advance science and health, and for policies that support responsible animal research.

The annual Research!America Advocacy Awards program was established by the Board of Directors in 1996 to honor outstanding advocates for medical, health and scientific research. Recognized individuals and organizations are those whose leadership efforts have been notably effective in advancing our nation’s commitment to research.

2015 Advocacy Awards Honorees

The promise of research
The American Association of Colleges of Pharmacy (AACP) Academic Research Fellows say they plan to use tips shared at a half-day advocacy and communications workshop on November 19 hosted by Research!America to build stronger relationships with elected officials, potential funders, media and non-scientists. The workshop featured presentations by Research!America staff on the latest developments in Congress on proposals relevant to AACP’s mission, recommendations on how to connect with policymakers, public perception of science and scientists, and interactive sessions on fine-tuning communications techniques such as message development and elevator speeches. MedPage Today news editor Joyce Frieden was a guest speaker for the program. She encouraged the Fellows to work with their communications colleagues in crafting compelling pitches for reporters on research issues that would be of interest to their readers.

Research!America partnered with United for Medical Research!America to convene a bipartisan congressional breakfast meeting in the Longworth House Office Building on May 7 for freshman members of Congress to meet National Institutes of Health (NIH) director Francis Collins, M.D., Ph.D. Mary Woolley, president and CEO, Research!America, Margaret Anderson of FasterCures and United for Medical Research!America’s David Pugach each gave brief remarks welcoming the group and explaining the role their respective organizations play in advocating for NIH and research broadly.

The event’s congressional hosts, House Energy and Commerce Chairman Fred Upton (R-MI) and Ranking Member Frank Pallone (D-NJ), not only kicked off the conversation, but also actively participated in the session. The briefing was held two days after the release of the second legislative draft and one day after the House Energy and Commerce Health Subcommittee hearing on the 21st Century Cures Act (H.R. 6).

Dr. Collins provided an overview of NIH, emphasizing its role funding research across all 50 states through the peer-review system. He highlighted areas of promising research, particularly precision medicine and the BRAIN initiative. Finally, he explained how declining budgets have adversely affected discovery and researchers. Members of the freshman class had the opportunity to ask the director specific questions and provide feedback, demonstrating their interest in ensuring a strong future for NIH and the research ecosystem as a whole.

The discussion touched on the importance of basic research, the future of precision medicine, improvements in clinical trials, and the need for greater use of electronic health records. The panelists impressed researchers and policymakers to think about how the research continuum can be streamlined to increase efficiency, and emphasized that health services research is key to implementing medical advances in the real world.

Opening the discussion, Denise Sullivan, a Woman-Heart Champion and heart disease survivor, shared her story and history of family losses associated with heart disease. Sullivan stressed that without funding for heart disease research, she would not be alive today.

Other panelists included: Shobha Ghosh, M.D., professor at Virginia Commonwealth University Medical Center; Andrew Zalewski, M.D., vice president and head of the cardiometabolic therapy area at GlaxoSmithKline; and Harry P. Saller, M.D., M.S.P.H., dean of Tufts Clinical and Translational Science Institute at Tufts University.

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National Health Research Forum

Leaders representing various sectors of the research community expressed their views on legislative and regulatory challenges and our nation’s research infrastructure at the Newseum in Washington, D.C.

Regulatory Science

Regulatory science was the focus of the third panel, moderated by Frank Seeno, director of the George Washington University School of Media & Public Affairs; Larry Shapiro, M.D., Washington University in St. Louis, Research!America Board Member; Amy Comstock Rick, J.D., President & CEO; Food and Drug Law Institute, Research!America Board Member; Stephen Ostroff, M.D., Acting Commissioner, Food and Drug Administration; Marc Boutin, J.D., CEO, National Health Council; William Hart, M.D., Ph.D., Global Head, Janssen Research & Development, Research!America Board Member.

Public Health Issues

The second panel, moderated by Seema Yasmin, M.D., medical analyst at CNN, looked at the prevalence of chronic conditions, antimicrobial resistance, telemedicine, vaccines, emerging public health issues and challenges of communicating the value of public health and health services research. The panelists were Richard Kronick, Ph.D., director, Agency for Healthcare Research and Quality; Avni Jina, M.D., senior vice president and head of global medical affairs at Shire; Gary Gibbons, M.D., director, National Heart, Lung, and Blood Institute, National Institutes of Health (NIH); Ron Mobed, chief executive officer, Elsevier; Sudip S. Parikh, Ph.D., vice president and general manager of health & analytics, Battelle; and Vincent A. Forlenza, chairman, chief executive officer and president, BD.

Modern Medicine

The first panel, moderated by Seema Y asmin, M.D., medical analyst at CNN, focused on the rapidly changing landscape of modern medicine and discussed the relationship between patient advocates, industry, policymakers, and other stakeholders in ensuring the development of new treatments and technologies. The panel featured Ani Jina, M.D., senior vice president and head of global medical affairs at Shire; Gary Gibbons, M.D., director, National Heart, Lung, and Blood Institute, National Institutes of Health (NIH); Ron Mobed, chief executive officer, Elsevier; Sudip S. Parikh, Ph.D., vice president and general manager of health & analytics, Battelle; and Vincent A. Forlenza, chairman, chief executive officer and president, BD.

ResearchAmerica’s 2015 National Health Research Forum, held in September at the Newseum, brought together a diverse group of panelists from industry, academia, patient groups, research institutes and government for wide-ranging discussions on the theme “Straight Talk: Advocacy for a New Era in Science.” Jeffrey Bloss, M.D., senior vice president of scientific and medical affairs, Astellas Pharmaceuticals U.S., lead sponsor of the event, discussed the importance of collecting, analyzing and disseminating real-world evidence, and engaging in value-based decision making.

More than 300 research advocates from across the country urged Congress to make funding for the National Institutes of Health (NIH) sustainable and predictable during the 2015 Rally for Medical Research Hill Day on September 17. ResearchAmerica was a lead supporter for the event which focused on making investments in biomedical research a higher national priority. Established and led by the American Association for Cancer Research (AACR), the two-day program featured remarks from NIH Director Francis Collins, M.D., Ph.D., and members of Congress including Chairman Tom Cole (R-OK), Senator Jerry Moran (R-KS), Senator Dick Durbin (D-IL), Senator Patty Murray (D-WA), Senator Amy Klobuchar (D-MN) and Congressmen Brian Higgins (D-NY). In his floor speech to Congress, Higgins cited a National Cancer Institute report “that identifies research that won’t be conducted unless Congress restores its purchasing power with sustained annual funding increases over the next decade. We must not let that happen.” ResearchAmerica president and CEO Mary Woolley and board member Dr. Mary Hendrix, Ph.D., president and CEO of the Stanley Manne Children’s Research Institute, spoke at the Rally reception.

Research!America was a lead supporter for a rally focused on making investments in biomedical research a higher priority.
During the 2016 election, Research!America and partners are encouraging candidates running for national office to share their views on medical and health research with voters as part of the national voter education initiative, Campaign for Cures: Vote for Medical Progress. The campaign works to elevate medical progress and policies that support private sector innovation in the national conversation. By arming voters with information on the health and economic benefits of medical research, the campaign galvanizes research advocates to ensure their voices are prominent on the campaign trail.

A majority of respondents (86%) say presidential candidates should participate in a debate to discuss key science-based challenges facing the United States, such as health care, climate change, energy, education, innovation and the economy, according to a national public opinion survey commissioned by Research!America and ScienceDebate.org.

Research!America also partnered in an event to help voters understand the complexity of the federal budget and determine what they consider to be priorities for federal spending. A group of about 100 Iowa voters discussed federal spending and structural reforms to the federal budget at an interactive budget exercise on September 22 at Drake University in Des Moines conducted by The Concord Coalition. Mary Woolley, Research!America president and CEO, participated in the program and described the impact of sequestration, automatic spending cuts, and policies that hinder private sector innovation, on achieving medical progress.

Through continued strategic activities, communications initiatives and partnerships with preeminent voter education groups, the campaign will increase public awareness of the research ecosystem and the role of the public and private sector in the discovery, development and delivery of lifesaving treatments to patients. For more information visit, www.campaignforcures.org.

As a guest speaker for Janssen Pharmaceuticals’ Town Hall on November 12, Research!America president and CEO Mary Woolley underscored the importance of public-private partnerships to accelerate the pace of research and innovation. “Never Settle,” the theme of the town hall, not only inspires Janssen’s commitment to advancing medical innovation to benefit patients worldwide, but epitomizes the determination of advocates for research, she said.

During the program, livestreamed for Janssen employees worldwide, Woolley presented recent public opinion survey data, encouraged scientists to communicate with non-scientists, and underscored the importance of partnerships and collaboration between governments, industry and academic research sectors.

Mary Woolley presented recent public opinion survey data, encouraged scientists to communicate with non-scientists, and underscored the importance of partnerships and collaboration between governments, industry and academic research sectors.
In describing the benefits of nursing research, how do you frame the message to have substantive conversations with non-scientists? Participants at a Johns Hopkins University (JHU) of Nursing science communications workshop hosted by Research!America in October learned about different strategies for communicating the value of their research with various audiences.

The workshop, facilitated by Research!America staff, invited participants to draft elevator pitches describing the benefits of nursing research, how fast to cures

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odernizing the research ecosystem to accelerate the discovery, development and delivery of lifesaving treatments to patients was the focus of a panel discussion titled “How Fast to Cures?” hosted by POLITICO Pro Health Care Report at the Newseum in Washington, D.C. in October. Arthur Allen, POLITICO Pro eHealth editor, moderated the panel that featured: Mary Woolley, president and CEO, Research!America; Mary Woolley, president and CEO, Research!America; Margaret Anderson, executive director, FasterCures; Joel White, executive director, Health IT Now; and Diana Zuckerman, Ph.D., president, National Center for Health Research. The panelists discussed the 21st Century Cures Act approved by the House, specific provisions such as health IT, funding for the Food and Drug Administration and the National Institutes of Health, and potential Senate action on the bill. A smaller package of bills in the Senate was one of the options raised by the panel. The discussion also highlighted the role of precision medicine to tailor treatments for individual patients, and concerns that the bill might loosen FDA standards to determine the safety and efficacy of new drugs and devices. The panel agreed that additional funding for the FDA and NIH was critical to implement provisions in the bill.

encouraging department chairs to lead research advocacy

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Recognizing public health professionals who work tirelessly every day to protect us from disease, injury and other health threats.

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n the Monday before Thanksgiving every year, Research!America and other health organizations urge Americans to recognize public health professionals who work tirelessly to protect us from illness and injury. Public Health Thank You Day (PHTYD), November 23, honored the everyday heroes who are committed to preventing the spread of disease, combating superbugs, addressing the obesity epidemic, and protecting us from environmental hazards and other health threats. Research!America and partners highlighted public health themes such as oral health, mental health, vaccinations, and milestones in public health during the month of November. PHTYD received broad support on social media and other communications channels from the U.S. Surgeon General Vivek Murthy, M.D., M.B.A., Tom Frieden, M.D., MPH, director, Centers for Disease Control and Prevention and Francis Collins, M.D., Ph.D., director, National Institutes of Health. Partners included the American Public Health Association, American Dental Education Association, The University of North Carolina Gillings School of Public Health, American Veterinary Medical Association, the Consortium of Universities for Global Health, Association of Public Health Laboratories, Oral Health America, National Alliance for Hispanic Health, Society for Public Health Education, Emory University Rollins School of Public Health and Ohio State University’s College of Public Health.

Public health heroes in the spotlight

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encouraging department chairs to lead research advocacy

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Public health heroes in the spotlight

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Woolley penned an op-ed in *CO Roll Call* calling on Congress to pass the 21st Century Cures Act.


Research!America VP of Communications Suzanne Flibes urged Congress to give consideration to the 21st Century Cures initiative and other bipartisan proposals to advance research in a letter to the editor in *The Des Moines Register*.

A USA Today insert featured an op-ed about clinical research penned by Woolley encouraging all research stakeholders to make patient participation in clinical research a “healthy behavior.”

In a letter to the editor in *USA Today*, in response to an article about the need for presidential candidates to have a detailed plan on how they would improve the diagnosis, treatment, and prevention of mental illness and addiction, Woolley added that plans should also include a commitment to boosting public support for research.

Woolley penned an op-ed in *The Huffington Post* about the lack of detailed policy solutions to advance medical progress for candidates.

Woolley was an opposing the proposed strategy. The article was also featured in *NPR* and *U.S. News & World Report*.

Research!America also shared relevant and compelling advocacy messages on social media via Twitter and Facebook in coordination with members and supporters.
The Honorable John Edward Porter
Chair
Senior Advisor, Hogan Lovells US LLP
United States Representative (1980–2001)

*The Honorable Michael N. Castle
Vice Chair
Partner, DLA Piper, LLP
United States Representative (1993–2011)

Mary Woolley, Ph.D.
President
Chief Executive Officer
Research!America

E. Albert Reece, M.D., Ph.D., M.B.A.
Secretary
Vice President of Medical Affairs, The John Z. and Aiko Bowers Distinguished Professor and Dean, University of Maryland School of Medicine

Lucinda Maine, Ph.D., R.Ph.
Treasurer
Executive Vice President & CEO
American Association of Colleges of Pharmacy

Elizabeth Baker Keffer
Managing Director and Chief Network Officer
BDT Capital Partners

Debra R. Lappin, J.D.
Principal, FaegreBD Consulting

*Alan I. Leshner, Ph.D.
Chief Executive Officer Emeritus, American Association for the Advancement of Science

James L. Madaus, M.D.
Executive Vice President and Chief Executive Officer
American Medical Association

Mark McClellan, M.D., Ph.D., M.P.A.
Director, Duke-Robert J. Margolius, MD, Center for Health Policy, Duke University

*Hon. Kweisi Mfume
President
United States Representative (1993–2011)

*Keith R. Yamamoto, Ph.D.
Professor; Vice Chancellor for Science Policy and Strategy; Vice Dean for Research, School of Medicine, University of California, San Francisco

Laing Rogers Sisto
Community Leader

Gregory Sorensen, M.D.
Executive Chairman, IMRIS

*Keith R. Yamamoto, Ph.D.
Professor; Vice Chancellor for Science Policy and Strategy; Vice Dean for Research, School of Medicine, University of California, San Francisco

Jewell Jackson McCabe

In Remembrance

William G. Anlyan, M.D.
Chancellor Emeritus of Duke University, was a founding member of the Research!America board, serving from 1989 to 2002. Dr. Anlyan chaired the Board from 1992 to 1996, and continued as an active emeritus director until his death.

Constance Lieber served as a member of Research!America's board from 1994 to 2003. She received the Exceptional Contributions as a Volunteer Advocate for Medical or Other Health-Related Research Award in 2002 for her advocacy for mental health research, and as the founder of The Lieber Institute for Brain Development.

John F. Sherman, Ph.D.
Former Distinguished Leader at NIH, served as senior advisor to the Research!America Executive Committee and the Board of Directors from 1994 to 2004.

Hon. Louis Stokes, Esq.
Former Congressman and civil rights advocate, served on Research!America’s Board of Directors from 2007 to 2010, and was active until his death as an emeritus board member.

Alan Walton, Ph.D., celebrated biotech leader, served on the Research!America Board of Directors from 1999 to 2005, and as an advisor to the CEO until his death.

Jack Watters, M.D., Vice President for External Medical Affairs, Pfizer, was elected to Research!America’s board from 2010 until the time of his death. He was dedicated to the health of people worldwide.