



2017 ANNUAL REPORT

ADVOCACY WORKS!



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Research!America is the nation's largest 501(c)(3) alliance working to make research to improve health a higher national priority. Research!America's member organizations together represent the voices of more than 125 million Americans. Our public opinion surveys, advocacy programs, and publications reach the public and decision-makers to help advance medical, health and scientific research.

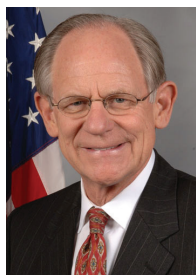
Letter from Leadership

Threats to science over the past months, including proposed funding cuts to federal science agencies, have ignited a spark in advocates to speak out more forcefully in support of all scientific disciplines, and engage the public and policymakers as never before. Even in a challenging environment, Research!America members, partners and friends contributed to noteworthy “wins” for research and innovation, such as the \$2 billion increase for the National Institutes of Health in FY17, passage of crucial FDA user fees legislation, preserving the Fogarty International Center and Department of Defense-funded medical research, making the R&D tax credit permanent and suspending the medical device tax for two years.

In addition, we collaborated as never before with organizations across the broad science enterprise to urge Congress to lift austerity-level budget spending caps and bolster research and development. Our *Raise the Caps* campaign featuring print ads and extensive social media attracted many co-sponsors and helped raise the visibility of science anew among undeniable public priorities. Also new and noteworthy in 2017, tens of thousands of scientists and supporters celebrated the role of science in society at the March for Science events in Washington, D.C. and in cities across the country and the world. Our award-winning video, *Science is a Field of Dreams*, was shown at the March for Science rally on the National Mall, and viewed on digital platforms. We are supportive of the 2018 March for Science, which will take place on April 14, shining an even brighter spotlight on science as it works to assure the health, security and economic prosperity of Americans.

To call attention to the cutting-edge research taking place in local communities, Research!America collaborated with Shepherd University for a program on the health and economic impact of research in West Virginia. The role of higher education and research in stemming the devastating tide of the opioid epidemic was a paramount focus. Senators Joe Manchin (D-WV) and Shelley Moore Capito (R-WV) described the challenges of combatting the crisis in their state and across the country; they also shared examples about the value of research in saving lives and strengthening the local economy. A strong majority of West Virginians (77%) support increased federal funding for research to better understand and combat the opioid addiction. This sentiment holds true in national surveys as well, as the epidemic continues to destroy the lives of countless individuals and their loved ones. In partnership with member organizations and supporters, we have and will continue to facilitate more state-based programs to raise awareness about the tangible and intangible benefits of research all across the nation.

The opioid epidemic, Alzheimer’s disease, cancer, and infectious diseases are among the many health threats that research and innovation are poised to conquer—if scientists have adequate, sustained support via funding and policies aimed at driving rather than stifling innovation. This election year is a time to amplify our messages about the value of public and private sector research. The question that should be on the lips of every voter is what a candidate will do, if elected, to accelerate medical progress. We must hold elected officials accountable and urge them to assign a higher priority to medical and health research, and prevention. The nation can afford no less.



The Honorable
Michael N. Castle
Chair

A handwritten signature in cursive script that reads "Michael N. Castle".



Mary Woolley
President and CEO

A handwritten signature in cursive script that reads "Mary Woolley".

Advocacy Overview

In 2017, Research!America and our more than 400 alliance member organizations worked hard to secure funding and policy priorities aimed at speeding medical progress, strengthening our nation's public health system, and in other ways advancing U.S. research and innovation.

Our advocacy efforts in 2017 contributed to or laid the groundwork for several key funding and policy accomplishments, including a \$2 billion increase for the National Institutes of Health (NIH) in FY 2017 and a two year suspension of the medical device excise tax. Our efforts also played a role in preventing a number of harmful proposals from advancing, among them: a one-size fits all cap on the indirect costs of federally-funded research, the elimination of the NIH Fogarty International Center, and the de-funding of the Agency for Healthcare Research and Quality (AHRQ).

We participated in 203 congressional meetings and held 26 meetings with Executive branch officials. Research!America facilitated more than 4,800 messages to Congress—a 62% increase over 2016. We published 43 new fact sheets, infographics, and other advocacy and public education materials, including a new fact sheet series highlighting the value of key federal health and research agencies. We sent or signed onto 63 letters and statements directed to members of Congress or the Administration, including letters advocating for robust fiscal year 2017 and 2018 funding for health and other scientific research, calling for repeal of the medical device excise tax, and opposing legislation that would compromise the efficiency and effectiveness of the Department of Defense Congressionally Directed Medical Research Program (CDMRP). A congressional sign-on letter we spearheaded on the need to raise the prevailing budget caps garnered more than 200 signatures.

COMMUNITY ENGAGEMENT

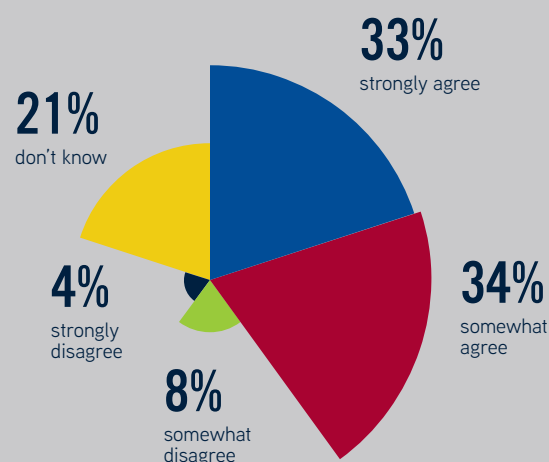
Research!America held more than 54 special events highlighting how research drives innovation, including three standing-room only Capitol Hill briefings showcasing the interplay of public and private sector-funded R&D underlying medical progress. Through the advocacy engagement platform on our website, we provided a host of resources for hands-on advocacy, including editable emails and tweets, talking points and phone scripts. We held meetings for alliance members that featured content experts on the appropriations process, tax reform, the Bayh-Dole Act, the indirect costs of research and other timely issues, and hosted meetings and calls that gave our members an opportunity to hear from key appropriations and authorizing committee staff.

LOOKING AHEAD

In 2018, Research!America will continue to expand and diversify our advocacy efforts as we fight for the funding and policies needed to fuel faster public and private-sector medical discovery; a public health system that is fully equipped to meet its lifesaving mission; health services and social sciences research that is pivotal to the future of health and health care; and, a stronger national commitment to our nation's unparalleled science and engineering enterprise.

Do you agree or disagree that public policies should be based on the best available science?

SOURCE: A RESEARCH!AMERICA SURVEY OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2018





U.S. Investments in Medical and Health Research and Development

Industry accounts for a huge percentage of medical and health research and development (R&D) spending in the U.S.—67% in 2016. Total investments across sectors grew by 20.6% from 2013–2016 but still make up just 4.9% of the total \$3.5 trillion in U.S. health spending, according to Research!America's report *U.S. Investments in Medical and Health Research and Development*.

"The uptick in investments is positive, but as a percentage of total U.S. health spending, investment in research remains stagnant," said Research!America's Chair The Honorable Michael Castle. "If we are to get out in front of the costly toll of disease we must ramp up our commitment to putting research to work to find solutions to the opioid epidemic, Alzheimer's disease, cancer and other deadly health threats."

Federal government investments increased 12.8% from 2013–2016, fueled largely by increases in the National Institutes of Health (NIH) budget. Academic research

institutions increased their medical and health R&D investments by 16.6%, and state and local governments increased their investments by 12% over the same period. Non-research conducting grant giving entities had a more modest increase of 4.7%.

"After years of decline, R&D investments are growing but not across all sectors in the robust way necessary to ensure the pace of scientific progress," said Mary Woolley, president and CEO, Research!America. "We haven't come close to recouping the almost 25% loss in purchasing power that NIH alone experienced in the previous decade; meanwhile, patients are waiting."



Raise the Caps Joint Campaign

Research!America ramped up advocacy efforts to call attention to the threat of federal investments to advance science under spending caps. The alliance led a joint "Raise the Caps" ad, digital, and grassroots campaign November 13–17, 2017 with several partner organizations, urging Congress to negotiate a budget deal to raise spending caps for both defense and non-defense programs. The Bipartisan Budget Act of 2015 provided relief from automatic budget cuts known as sequestration for two years but the budget caps were expected to return in FY18.

The robust campaign included full page print ads in *The Wall Street Journal*, *POLITICO*, *Washington Examiner* and *The Weekly Standard*, and digital ads in *The Hill*, *CQ Roll Call*, *washingtonexaminer.com*, *weeklystandard.com* and *DailyCaller.com*. The digital ad campaign generated more than 700,000 impressions, outpacing benchmarks compared to similar ad campaigns. Messages shared across social

media generated more than two million impressions with nearly 200 organizations participating.

Campaign partners for the November initiative included the American Association for the Advancement of Science, American Educational Research Association, American Geophysical Union, American Physical Society, Federation of American Societies for Experimental Biology, March for Science, National Association for Biomedical Research, OSA-The Optical Society, Society for Neuroscience, and Supporters of Agricultural Research Foundation.





Joe Biden, 47th Vice President of the United States

2017 Advocacy Awards

The 2017 Advocacy Awards honored outstanding advocates for research whose contributions have revolutionized cancer research, increased public awareness of lupus and lymphedema and lymphatic diseases, contained infectious disease outbreaks, led to landmark legislation to accelerate the pace of new medical advances, and much more. The honorees were recognized for their achievements in research advocacy on March 15 at the Andrew W. Mellon Auditorium in Washington, D.C.

LEGACY AWARD

Anthony S. Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases, who has worked tirelessly to prevent, diagnose, and treat infectious and immune-mediated diseases. Dr. Fauci has advised every Administration since President Reagan on a myriad of public health threats from AIDS to Ebola to Zika.

EDWIN C. WHITEHEAD AWARD FOR MEDICAL RESEARCH ADVOCACY

Senator Lamar Alexander (R-TN) for his leadership in advancing research and innovation. Sen. Alexander was instrumental in congressional passage of the 21st Century Cures Act, and has served as Chairman or Ranking Member of the Senate Health, Education, Labor & Pensions (HELP) Committee since 2007, and in that capacity has shepherded legislation crucial to the discovery, development and delivery of new medical advances.

GORDON AND LLURA GUND LEADERSHIP AWARD

Joe Biden, 47th Vice President of the United States, for his commitment to accelerating cancer research as the driving force behind the White House Cancer Moonshot. The Cancer Moonshot, and now the Biden Cancer Initiative, aim to speed the pace in which effective therapies are made available to patients and improve efforts to prevent and detect cancer at an early stage.

ISADORE ROSENFELD AWARD FOR IMPACT ON PUBLIC OPINION

Award-winning actress Kathy Bates, Lymphatic Education & Research Network (LE&RN) spokesperson, for raising the visibility of lymphedema and lymphatic diseases and advocating on behalf of the patient community. Ms. Bates has brought lymphedema and lymphatic diseases into the spotlight in the media, including the first-ever profile of a patient receiving lymphedema treatment, which aired on *CBS Sunday Morning*.

GEOFFREY BEENE BUILDERS OF SCIENCE AWARD

Leland H. Hartwell, Ph.D., Nobel Laureate and director of the Pathfinder Center at Arizona State University's Biodesign Institute and Virginia G. Piper Chair of Personalized Medicine, for his leadership and determination in building an outstanding scientific research organization as president and director of the Fred Hutchinson Cancer Research Center (FHCRC) from 1997 to 2010.

RAYMOND AND BEVERLY SACKLER AWARD FOR SUSTAINED NATIONAL LEADERSHIP

Phillip A. Sharp, Ph.D., Nobel Laureate and Institute Professor at the Massachusetts Institute of Technology, for his powerful advocacy efforts for cancer research, serving as Chairman of Stand Up To Cancer's (SU2C) Scientific Advisory Committee since the organization's inception in 2008.

PAUL G. ROGERS DISTINGUISHED ORGANIZATION ADVOCACY AWARD

The Lupus Foundation of America as the nation's leading nonprofit voluntary health agency dedicated solely to lupus by providing national, state, and local programs through a nationwide network of chapters and support groups. The Foundation provides national leadership for lupus research, patient and professional education, and public awareness.



(L to R) Kathy Bates; Harold L. Paz, M.D., M.S.



(L to R) Anthony S. Fauci, M.D.; The Hon. John Edward Porter, Research!America Chair Emeritus



(L to R) Tom Hutton; Mara Hutton; Leland H. Hartwell, Ph.D.



(L to R) Sandra Raymond, Lupus Foundation of America; Sue Manzi, M.D., MPH; Pippy Rogers; Allie Gutshall; The Hon. Kweisi Mfume



(L to R) Jonathan Sackler; Phillip Sharp, Ph.D.; Rush Holt, Ph.D.



(L to R) Emma Detlefsen and Kathy Bates

Advocates Voice Support for Health Research at Research!America's Annual Meeting

The benefits of medical research extend beyond improving the health of Americans. "We know that the [National Institutes of Health] supports over 400,000 jobs across America," said Rep. David McKinley (R-WV-01). "Every year NIH writes grants for \$32 billion a year. That's significant." Rep. McKinley also noted that research is critical to economic growth and maintaining our global leadership in science and technology. He was among the speakers at Research!America's 28th Annual Meeting of Members on March 15 in Washington, D.C.

Award-winning actress and Lymphatic Education & Research Network (LE&RN) spokesperson Kathy Bates also voiced support for federally-funded medical research and called on Congress to pass legislation that would help cover the cost of lymphedema compression garments. She shared the story of her personal struggle with the disease.

"Ten million Americans suffer from lymphedema," Bates said. "That's more than MS, muscular dystrophy, ALS, Parkinson's and AIDS combined. But nobody knows about lymphedema." Some of those with lymphedema "suffer daily, often with terrible physical and emotional pain" while waiting for the correct diagnosis.

Bates brought to the stage eight-year-old LE&RN youth ambassador Emma Detlefsen—whom she called her "personal hero"—and together they encouraged lawmakers to support funding for research.

The meeting's panel discussion focused on advances in lupus research. Allie Gutshall, a patient advocate and Lupus Foundation of America volunteer, recounted the weeks of fevers, swollen joints, migraines and pain she experienced during her senior year of college before being diagnosed with lupus, after visiting eight different doctors.

"Fifty percent of lupus patients go on disability within three years of their diagnosis," said Dr. Christopher Collins, a rheumatologist at MedStar Washington Hospital Center. He said greater investments in medical research could result in new drugs, allowing more patients to remain in the workforce.

Sue Dillon, Ph.D., Global Therapeutic Head, Immunology, Janssen Research & Development, said researchers could use the Cancer Moonshot's approach of collaboration as a model for tackling diseases like lupus.

Supporting Research to Tackle Addiction and Fuel Economic Growth in West Virginia

Research!America's program "West Virginia Research and Innovation: A Catalyst for Better Health and Economic Growth" explored how West Virginia and local research institutions could leverage their assets to strengthen the local economy and tackle health threats such as the opioid epidemic. The event, held on October 16 at Shepherd University, included panelists and speakers from academia, industry and government.

Senator Joe Manchin (D-W.Va.) discussed the impact of the opioid crisis on the workforce. "Every job fair we had over 100 employers looking to hire, but everybody walks away not finding the people they need," he said. "There are three things keeping you out of the workforce: addiction, conviction or lack of skill set." Manchin added that bipartisanship in Congress is key to successfully addressing addiction, and that doing so will help ensure adequate staffing of jobs created from more public and private-sector investments in the state.

Universities should be at the leading edge of providing expertise in research and technology to combat drug abuse, said Senator Shelley Moore Capito (R-W.Va.) who described West Virginia as "ground central" in the opioid epidemic. Federal research dollars must be distributed to smaller lesser-known universities in the state, she added. A strong majority of West Virginians agree that federal taxpayer funds should be used to support scientific research at public universities (77%), and that the state and federal government should assign a higher priority to improving science, technology, engineering and math (STEM) careers (85%), according to a state survey commissioned by Research!America.

Brad Fenwick, Ph.D., senior VP, global strategic alliances, Elsevier, said that in order to attract more companies, West Virginia must inform investors and businesses about its research strengths, including the state's leadership in nanotubes, carbon and nanostructures.

Mary J.C. Hendrix, Ph.D, president, Shepherd University, described the forum as "a wonderful opportunity to exchange ideas" from which West Virginia and the whole region could benefit.



(L to R) Senator Shelley Moore Capito (R-W.Va.) and Mary J.C. Hendrix, Ph.D., president, Shepherd University



Senator Joe Manchin (D-W.Va.)

(L to R) Brad Fenwick, Ph.D.; Cannon Wadsworth; Fred White; Marcia Brand, Ph.D.; Lieutenant Colonel Adelaido Godinez; Judy Miller Jones





Washington, D.C. March for Science

March for Science

Research!America joined scientific organizations across the country and abroad as a partner for the March for Science on April 22, a global non-partisan movement to raise awareness about the role of science in society. The event was held in 600 cities and hundreds of thousands of scientists and science enthusiasts participated in marches and events. Research!America staff joined marches in Washington, D.C., Los Angeles, CA, Oklahoma City, OK, and Salt Lake City, UT.

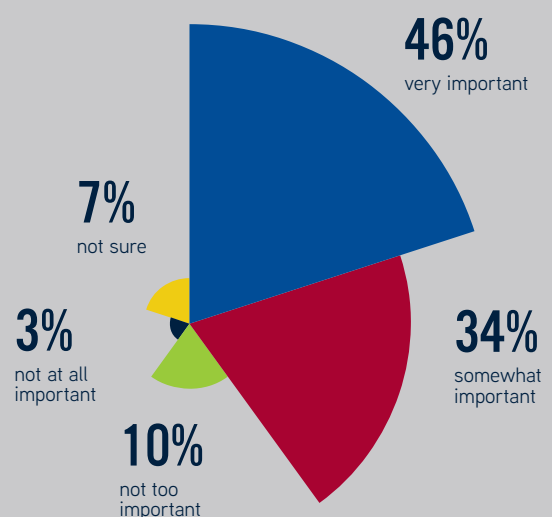
The rally and march on the National Mall in Washington, D.C. included a video featuring Research!America president and CEO Mary Woolley and science policy fellow Anna Hatch, Ph.D. "Science is a field of dream for all of us...everyone who cares about the future of health and economic prosperity in this country must speak up now," said Woolley in the video. Dr. Hatch described research aimed at better understanding cancer metastasis.

Research!America board members Rush Holt, Ph.D., CEO of the American Association for the Advancement of Science and Georges Benjamin, M.D., director of the American Public Health Association, were among the March for Science speakers in D.C. Dr. Holt spoke in support of leveraging science to help shape decision making in Congress, "Today, thousands of people from all walks of life...are saying that evidence verified by science is the only reliable way to make public policy." Dr. Benjamin noted that science is necessary to improve public health, "A strong commitment to research is absolutely essential to draft the evidence-based solutions that protect us from serious health threats."

Research!America March for Science buttons were distributed at the satellite marches and the event in Washington D.C.

How important is it for candidates running for Congress to have a basic understanding of scientific issues?

SOURCE: A RESEARCH!AMERICA SURVEY OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2018





(L to R) Marilyn Serafini; Anne Schuchat, M.D.; Seth Ginsberg; Gopal Khanna; Lucinda Maine, Ph.D., R.Ph.; The Hon. Patrick Kennedy; Governor Charlie Baker

Is a Disease-Free World Within Reach?

2017 National Health Research Forum

The U.S. is a leader in worldwide R&D but sustained funding levels for the National Institutes of Health (NIH) and a regulatory system built for the 21st century are critical to build on our success. Mikael Dolsten, M.D., president of worldwide research & development, Pfizer, shared insights on the future of innovation in a keynote address at Research!America's National Health Research Forum on September 7 in Washington, D.C., Stronger partnerships between the public and private sector would help ensure patients have access to new medicines as a result of new discoveries, he said. The program featured panel discussions with top leaders in government, industry, patient advocacy and academia. Pfizer Inc was the lead sponsor of the event.

ADDRESSING ESCALATING HEALTH THREATS: THE ROLE OF RESEARCH IN COMBATING THE OPIOID CRISIS AND OTHER URGENT COMMUNITY HEALTH CHALLENGES

Panelists explored the role of research in understanding and addressing the opioid epidemic, noting that medical education must improve to ensure providers address opioid addiction based on the best available research.

MODERATOR: Marilyn Serafini, health care policy consultant

PANELISTS: Governor Charlie Baker, 72nd Governor of Massachusetts; Seth Ginsberg, co-founder and president, Global Healthy Living Foundation; The Hon. Patrick Kennedy, U.S. Representative, 1995–2011; Gopal Khanna, director, Agency for Healthcare Research and Quality; Lucinda Maine, Ph.D., R.Ph., executive vice president and CEO, American Association of Colleges of Pharmacy; Anne Schuchat, M.D., principal deputy director, Centers for Disease Control and Prevention

REMARKS AND Q&A WITH FDA COMMISSIONER SCOTT GOTTLIEB, M.D.

Scott Gottlieb, M.D., commissioner, Food and Drug Administration (FDA), said the Food and Drug Administration is exploring abuse-deterrent drug formulations, medically assisted therapies, and non-addictive pain products to help reduce addiction rates. Gottlieb also announced that the agency is modernizing the way it reviews new drug applications particularly those involving gene and cell therapy. "Our aim is to make sure our policies match the sophistication of

the science we're asked to evaluate, and help enable this new paradigm of beneficial innovation," he said.

FAILING FASTER AND OTHER SUCCESSES: AN UPDATE ON EFFORTS TO SPEED MEDICAL PROGRESS

The second panel focused on regulatory science, patient perspectives in research and barriers to innovation. Panelists discussed efforts to speed medical progress utilizing new technologies and tackling health disparities.

MODERATOR: Byron Pitts, anchor & chief national correspondent, ABC News

PANELISTS: Joel W. Beetsch, Ph.D., vice president of global patient advocacy, Celgene; Nancy Brown, chief executive officer, American Heart Association; Victor Dzau, M.D., president, National Academy of Medicine; Mark B. McClellan, M.D., Ph.D., MPA, director, Duke-Robert J. Margolis, MD, Center for Health Policy, Duke University; Joe V. Selby, M.D., MPH, director, Patient-Centered Outcomes Research Institute; Scott Whitaker, president and CEO, AdvaMed

ENDING DISEASE: WHAT'S POSSIBLE? PROBABLE? WITHIN REACH?

Is a disease-free world possible? Panelists described ways in which precision medicine, social determinants of health, universal vaccines, behavioral research and technological advances play critical roles in halting the progression of disease.

MODERATOR: Jeanne Cummings, deputy Washington bureau chief, *Wall Street Journal*

PANELISTS: Ann Cary, RN, MPH, Ph.D., FNAP, dean, University of Missouri-Kansas City School of Nursing and Health Studies; Francis S. Collins, M.D., Ph.D., director, National Institutes of Health; Mikael Dolsten, M.D., Ph.D., president, worldwide research & development and executive vice president, Pfizer; William Hait, M.D., Ph.D., global head, Johnson & Johnson External Innovation; Iris Loew-Friedrich, M.D., Ph.D., chief medical officer, UCB; David E. Neal, CBE, FMedSci FRCS, senior vice president of global academic research, Elsevier; Gary Reedy, chief executive officer, American Cancer Society

A World Without Disease

How can we capitalize on insights from the biotechnology industry and facilitate a coordinated effort to eradicate disease? That was the main question discussed during an interactive panel, “A World Without Disease: Can We Get There?,” at the BIO International Conference in San Diego, California on June 20.

Donna Cryer, president and CEO of the Global Liver Institute suggested that this ambitious goal is within reach. “Nine thousand days ago, doctors told me I had seven days to live,” said Cryer. “I believe in our ability to continually adapt and innovate and conquer disease.”

Cryer was joined by Research!America board member Dr. William Hait, global head, Johnson & Johnson External Innovation, and fellow board member Dr. Mark McClellan, director, Duke-Robert J. Margolis Center for Health Policy, Duke University. Luke Timmerman, founder and editor, Timmerman Report, moderated the panel.

Panelists agreed that disease eradication requires an effective research pipeline that prioritizes prevention. Collaboration is also critical, allowing researchers to aggregate and utilize research data more quickly.

“The big steps are going to come from researchers and people with big ideas,” McClellan said. He expressed the need for a payment system that incentivizes prevention and detection.

“It takes a long time to bring a drug through the development process,” said Hait. “When you start that journey, you want to be sure that you exceed some market expectations 10 years from now... there is a lot we can do with information and tools in preventive ways.”

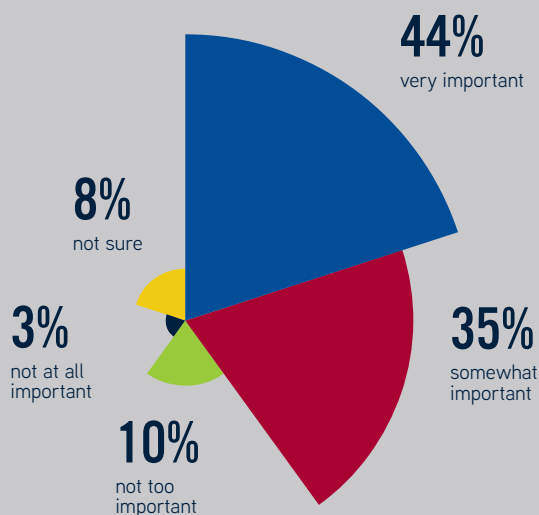
McClellan also noted that funding the National Institutes of Health is crucial to eradicating disease, and said he is proud of the work that Research!America and others have done to rally strong, bipartisan congressional support for NIH funding.



(L to R) Donna Cryer, Luke Timmerman, Mark McClellan, M.D., Ph.D., MPA, William Hait, M.D., Ph.D.

How important is it for the federal government to support incentives for private sector investment in new treatments and cures?

SOURCE: A RESEARCH!AMERICA SURVEY OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2017





(L to R) Victor J. Dzau, M.D.; Sudip S. Parikh, Ph.D.; Patty Fritz, MS; John Hubbard, Ph.D., FCP; Eleanor M. Perfetto, Ph.D., M.S.

Research Continuum Congressional Briefings

FROM DISCOVERY, DEVELOPMENT TO DELIVERY

Research and development involves collaboration, investments and risk to ensure new treatments benefit patients, according to panelists at a Capitol Hill briefing on February 14 hosted by Research!America and the Congressional R&D Caucus. The briefing “Medical Innovation 101” highlighted various aspects of the research continuum from basic to post-market research; basic science, clinical and translational research, health services research and health economics and the patient community.

Among the panelists were Research!America board member Keith Yamamoto, Ph.D., Vice Chancellor for Science Policy and Strategy, University of California San Francisco; Brian Gill, Vice President of Corporate Affairs, Celgene; and Joe Selby, MD, MPH, Executive Director, Patient-Centered Outcomes Research Institute (PCORI).

CLINICAL RESEARCH

“Clinical trial design, cost, regulatory burden and recruitment are some of the challenges associated with clinical research,” said Victor J. Dzau, M.D., president, National Academy of Medicine and Research!America board member. Dzau joined other experts in basic science, clinical and translational research and patient advocacy to explore developments in clinical research during a Research!America Capitol Hill Briefing titled “Innovation Intersection” on June 12.

Panelists included Patty Fritz, M.S., vice president of U.S. Corporate Affairs, UCB Inc.; John Hubbard, Ph.D., FCP, chairman, Association of Clinical Research Organizations (ACRO), president and CEO, Bioclinica; and Research!America board member Sudip S. Parikh, Ph.D., senior vice president and managing director, DIA Americas; and others.

MIGRAINE RESEARCH

Experts across different areas of migraine research and treatment came together to discuss the societal burden of this debilitating disease during a panel discussion on June 15. Walter Koroshetz, M.D., director of the National

Institute of Neurological Disorders and Stroke (NINDS), described how the BRAIN initiative and current research have made significant progress in identifying causes of migraines.

Other speakers included Mary Franklin, executive director of the National Headache Foundation; Jaime Sanders, a patient advocate and blogger; and Amaal Starling, M.D., an associate professor and physician at the Mayo Clinic.

ALZHEIMER'S DISEASE

Experts in medical research, public health and disease advocacy discussed progress in Alzheimer's disease research during a briefing on October 5. Panelists, however, noted challenges with translating research into clinical practice and identifying biomarkers that predict disease onset and progression.

Speakers included Robert Egge, chief public policy officer and executive vice president of government affairs, Alzheimer's Association; Richard Hodes, M.D., director, National Institute on Aging (NIA); Michael C. Irizarry, M.D., MPH, vice president of early clinical development, neurosciences, Eli Lilly; and Rosebud Roberts, M.B., Ch.B., chair of the Mayo Clinic Division of Epidemiology, among others.

COPD RESEARCH AT WORK

Nearly 16 million Americans are living with COPD, which is the leading cause of death in the U.S. following heart disease and cancer. Dr. Gary Gibbons, director of the National Heart, Lung, and Blood Institute (NHLBI), stressed the urgent need for increased awareness, better diagnosis, prevention and treatments for COPD, during a briefing on November 15 that highlighted ongoing challenges with COPD research funding and access to treatment.

Panelists included Grace Anne Dorney Koppel, JD, M.A., president, Dorney-Koppel Foundation; Lisa Simpson, MB, BCh, MPH, FAAP, president and CEO, AcademyHealth; Dr. David Mannino, U.S. Respiratory Medical Expert, GlaxoSmithKline, and others.



Mary Woolley, President and CEO, Research!America

Your Role in Changing Hearts and Minds for Science

Research!America President and CEO Mary Woolley urged scientists to talk to relatives, friends and lawmakers about their research to help combat what she called “the invisibility of research” during a series of presentations supported by the Kavli Foundation at institutions across the country.

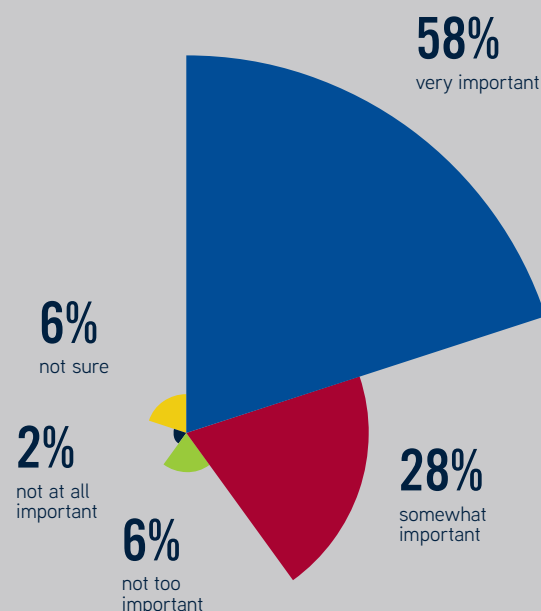
Scientists and research institutions continue to be largely invisible to society, according to a survey commissioned by Research!America. Only 16% of respondents say they can name a living scientist and less than a quarter know that medical research is conducted in all 50 states.

In sharing tips on how to build relationships with policymakers, Woolley noted that scientists must know who represents them in Congress. “Would you recognize your government representatives if you bumped into them at Starbucks?,” she asked. “Would they recognize you? If not, find out what they look like, be ready to thank them for their public service” and explain that you also work for the public.

In 2017, Woolley was a Kavli-sponsored keynote speaker at the University of North Carolina, Chapel Hill, Tennessee Conference of Graduate Schools, University of Michigan, University of Kentucky, University of Nebraska, University of Iowa School of Public Health, La Jolla Institute for Allergy and Immunology, and Albert Einstein College of Medicine.

How important is it for scientists to inform the public about their research and its impact on society?

SOURCE: A RESEARCH!AMERICA SURVEY OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2018



Research!America's Webinars

PUBLIC SUPPORT

Public support for science can have a profound effect on policies impacting the nation's scientific enterprise. Effectively communicating the health and economic benefits of science, the patient experience and recent discoveries that have potential policy implications is integral to connecting the dots with non-scientists.

To delve deeper into public attitudes about science, Research!America and the Society for Neuroscience hosted the webinar, "Leveraging Public Opinion in Support of Science" on December 4. Speakers included Mary Woolley, president and CEO, Research!America; Christopher Volpe, Ph.D., executive director, ScienceCounts; and Navneet Matharu, Ph.D., postdoctoral fellow, University of California San Francisco. The webinar was moderated by Anna Briseno, senior manager of communications, Research!America.



Fogarty International Center Researchers

OPIOID EPIDEMIC

At more than 40,000 deaths per year, opioid overdoses account for more loss of life than gun violence and motor vehicle accidents combined. On October 13, Research!America hosted the webinar, "Innovative Research and the Opioid Epidemic: Are We Closer to Finding Solutions?" Speakers discussed how researchers, public health officials and pharmacists serve pivotal roles in combating this public health crisis.

The webinar featured Nora Volkow, M.D., director, National Institute on Drug Abuse at the National Institutes of Health; Georges Benjamin, M.D., executive director, American Public Health Association; and Jeffrey Bratberg, Pharm.D., clinical professor, University of Rhode Island College of Pharmacy.

GLOBAL HEALTH

Diseases know no borders, as we've seen with Ebola, Zika, bird flu, SARS and other infectious disease outbreaks. The Fogarty International Center is on the front-lines, strengthening capacity in other countries to detect and address pandemics and forging global partnerships with scientists on the cutting edge of research. Research!America, the Infectious Diseases Society of America, and the American Society of Tropical Medicine and Hygiene hosted the webinar "The Fogarty International Center: How Americans Benefit from Global Health Research" on May 25.

Speakers included Roger Glass, M.D., Ph.D., director of The Fogarty International Center at NIH; Chris Beyrer, M.D., MPH, Johns Hopkins Bloomberg School of Public Health; Bob Bollinger, M.D., MPH, Johns Hopkins Bloomberg School of Public Health; and Christine Lubinski, vice president for global health, Infectious Diseases Society of America.

Honoring Public Health Heroes

On the Monday before Thanksgiving, November 20, leading public health organizations joined Research!America in honoring community health workers, epidemiologists, dentists, researchers, nurses and many more during Public Health Thank You Day. The work of public health professionals committed to fighting chronic diseases and epidemics like the opioid crisis and antibiotic resistance, and health threats from natural disasters was highlighted on various communications platforms including social media.

"Thank you to our public health heroes who work hard every day to improve our nation's health, including new partners like business, law enforcement, education and defense sectors," said Surgeon General Jerome Adams, M.D., in a tweet.

"Here at APHA (American Public Health Association), we are proud of and grateful for their service and honored to work alongside them in creating the healthiest

nation in one generation," said APHA President and Research!America board member Georges Benjamin, M.D.

Other notable Public Health Thank You Day participants included National Institutes of Health Director Francis Collins, M.D., Agency for Healthcare Research and Quality Director Gopal Khanna, Massachusetts Governor Charlie Baker, and World Bank President Jim Kim, M.D., Ph.D., and several members of Congress.

Co-chairs of the House Public Health Caucus, Representatives Jim McGovern (D-MA), Rob Wittman (R-VA), Kay Granger (R-TX), Gene Green (D-TX), and Lucille Roybal-Allard (D-CA), introduced a resolution (H.Con.Res.91) recognizing the public health workforce on Public Health Thank You Day. Rep. Steve Cohen (D-TN-9) also co-sponsored the resolution.

Visit WWW.PUBLICHEALTHTHANKYOU.DAY.ORG for a full list of 2017 partners.

The Science of Science Communication

Complex scientific issues ranging from genome editing to artificial intelligence must be communicated effectively to engage the public. The Arthur M. Sackler Colloquia of the National Academy of Sciences (NAS), The Science of Science Communication III held at NAS in Washington, D.C. November 16–17, highlighted studies aimed at making research-based communication the norm.

The theme, “Inspiring Novel Collaborations and Building Capacity,” aligns with the NAS study *Communicating Science Effectively: A Research Agenda* which includes recommendations for science communicators and researchers seeking to apply this research and fill gaps in knowledge on science communication, focusing on issues that are contentious in the public sphere.

During the colloquium, the study’s committee chair Alan Leshner, Ph.D., CEO Emeritus, American Association for the Advancement of Science and Research!America board member, told attendees that scientists need to “move from a monologue to a dialogue” with the public. Researchers from Dartmouth College and practitioners from the Vermont Department of Health, award recipients, presented their study on communicating the benefits of vaccines to hesitant parents. Suzanne Ffolkes, vice president of communications, Research!America, and other panelists shared insights on ways to strengthen the project, such as engaging different segments of the population and influencers in local communities.

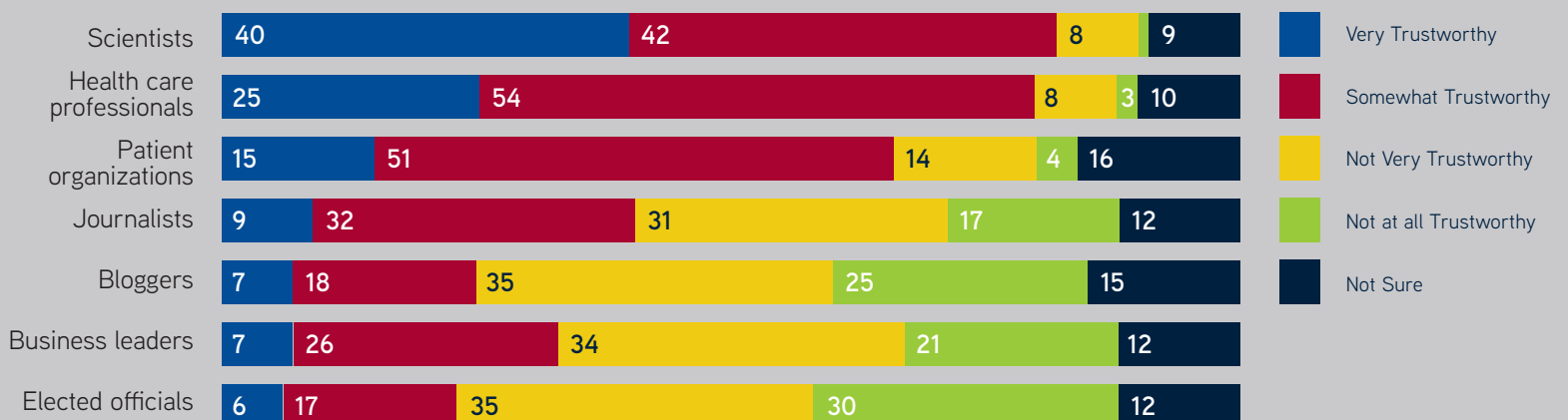


(L to R) Ashley Llorens; Doron Weber; Suzanne Ffolkes; Paul Hanle; Greg Boustead

In a separate discussion at the Research Universities Convocation hosted by the National Academies of Sciences, Engineering, and Medicine November 15, representatives from academia, research and scientific societies discussed cross-sector research partnerships. Mary Woolley, president and CEO, Research!America, said involving the public in research can help better align stakeholder priorities and ultimately strengthen partnerships. Woolley cited the Patient-Centered Outcomes Research Institute (PCORI) as an example of researchers successfully engaging patients to achieve shared goals.

How trustworthy do you consider each of the following to be as spokespersons for science?

SOURCE: A RESEARCH!AMERICA SURVEY OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2017



Media Highlights

Opinion pieces, compelling insights, and in-the-moment interviews about medical and health research funding and policies impacting public and private sector research contributed to Research!America's extensive media coverage in 2017. Online, print, broadcast and digital media highlights include:

A **NEW YORK TIMES** editorial featured Research!America president and CEO Mary Woolley's comments that President Trump's FY18 budget request for federal science agencies do not reflect the priorities of a nation committed to improving the health of citizens. Woolley also discussed the impact of the proposal on science in a **WASHINGTON POST** article.

Woolley's op-ed "Scientific Research Changes our Lives for the Better" was published in **THE MIAMI HERALD**.

Research!America Chair Emeritus The Honorable John Edward Porter penned a letter-to-the-editor stating that scientific facts should not be disputed and instructional science materials must continue to reflect evidence and data in the **WASHINGTON POST**.

THE AMERICAN JOURNAL OF TROPICAL MEDICINE AND HYGIENE published an op-ed authored by Chair Emeritus Porter urging support for federally-funded global health research.

Research!America Chair The Honorable Michael Castle was profiled in a **NEUROSCIENCE QUARTERLY** Q&A article and discussed the role of scientists in sustaining federal investments in medical and health research.

Woolley's letter-to-the-editor urging the repeal of the Budget Control Act of 2011 to empower the nation's scientific research enterprise was published in **THE WALL STREET JOURNAL**.

Research!America VP of Communications Suzanne Ffolkes penned a letter-to-the-editor published in **THE ST. LOUIS POST-DISPATCH** calling on Congress to pass a budget deal that lifts the spending caps on research.

Ellie Dehoney, Research!America VP of Policy and Advocacy, penned an op-ed in **MORNING CONSULT** about the importance of repealing the medical device tax.

In a **WEST VIRGINIA PUBLIC RADIO** news segment about research funding in the state, Woolley talked about the results of a survey commissioned by Research!America among West Virginians on a range of issues including the opioid crisis and research funding.

Research!America news, survey results, and advocacy messages were shared broadly and generated significant interest on social media.

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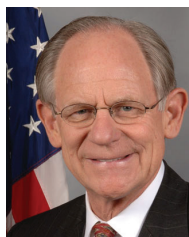
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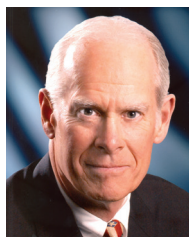
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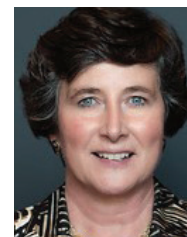
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IN MEMORIAM

Isadore Rosenfeld, M.D., (1926–2018) was widely recognized as one of the country's preeminent physicians and a renowned advocate for medical and health research. Dr. Rosenfeld was a founding board member of Research!America and established the *Isadore Rosenfeld Award for Impact on Public Opinion*, which honors members of the media or individuals who effectively deliver research advocacy messages to the public. He served as a consultant to the National Institutes of Health, and hosted the weekly "Sunday Housecall" on FOX News. His book, *Doctor of the Heart: My Life in Medicine*, recounts his extraordinary career as a cardiologist and "America's Doctor" during a time of great progress in medicine.

Raymond R. Sackler, M.D., (1920–2017) gifted physician, international philanthropist and lifelong champion of scientific research. Dr. Sackler was a founding board member of Research!America. The Raymond and Beverly Sackler Foundation and the Raymond and Beverly Sackler Fund for the Arts

and Sciences have sponsored research investigations at more than a dozen leading universities in the United States and abroad. Dr. Sackler was an early adopter and provided major philanthropic support of convergence research, the importance of mathematics, physics and engineering sciences in forging deeper understanding of biology, which led to advances in unraveling complexities of the human genome, nanotechnology and biological imaging.

Trish Vradenburg (1946–2017) was honored with the 2016 *Gordon and Llura Gund Leadership Award* along with her husband George. The Vradenburgs founded *UsAgainstAlzheimer's* (UsA2), an organization advancing solutions to Alzheimer's disease and a relentless force committed to ending Alzheimer's by 2020. Trish Vradenburg was the vice-chair of UsA2 and a founder of *WomenAgainstAlzheimer's*. She was also a playwright, author, comedy writer, journalist and advocate.



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