



Innovative Advocacy for Research



## Elevating Research and Innovation in the National Conversation

**As we reflect on our emphasis this past year** on putting medical and health research and policies for private sector innovation on par with defense and other national priorities, we pause to commemorate 25 years of high-impact advocacy. Some of our key contributions to advocacy for research over the past quarter-century are highlighted in this Annual Report, including our leading role in the doubling of the National Institutes of Health budget and being among the first to use public opinion polling to inform advocacy. With our global competitiveness at stake as other countries strengthen their R&D infrastructures, we must continue to forge on, full speed ahead, to increase funding and advance policies for medical innovation.

We know that research and innovation are essential to a healthier and more prosperous America. That is a wonderful story to be told and reinforced: to policy makers, whose decisions sow the progress that our research enterprise makes; to the public, whose support is critical in determining national priorities; and to media, whose megaphone helps galvanize public opinion.

Reaching these three audiences with impact is critical to successful advocacy. Our national voter education initiative in 2014 — Ask Your Candidates! Is Medical Progress a Priority? — will give candidates for federal office the opportunity to explain their views on medical innovation. We will help researchers, who are best equipped to tell the story, make the case for a better funding and policy environment. And our ongoing outreach and availability to media helps to ensure that medical research will not fade from the headlines or from the public's memory.

We thank Research!America's members and partners; your support and contributions are the heartbeat of our alliance. We look forward to working with you as we promote the health, economic and societal benefits of research to improve health. Here's to making the next years of our second quarter-century the high mark of our achievements to date!



A handwritten signature in black ink, appearing to read 'John Edward Porter'.

**The Honorable  
John Edward Porter**  
Chair



A handwritten signature in black ink, appearing to read 'Mary Woolley'.

**Mary Woolley**  
President and CEO



## Making a Stronger Case for Medical Innovation

**T**he benefits of medical innovation are many, and a critical component of Research!America's mission is ensuring that policy makers recognize the value and transformative power of our nation's research enterprise in saving lives, building a stronger economy and assuring our global leadership in science. In making the case for research on Capitol Hill, Research!America met with 82 Members of Congress or key staff in 2013. Among the offices we visited were those of Speaker John Boehner (R-OH), Senate Majority Whip Dick Durbin (D-IL), House Minority Leader Nancy Pelosi (D-CA), House Majority Leader Eric Cantor (R-VA), and Senate and House appropriators, including Labor-H subcommittee leadership.

Member meetings were part of a multifaceted advocacy strategy aimed at maximizing funding for agencies involved in medical, health and other scientific research; stopping sequestration; and promoting a policy environment conducive to robust private sector medical innovation. Research!America issued and signed on to 30 letters and statements in 2013 on topics such as eliminating sequestration, enumerating appropriation priorities, enhancing the research and development tax credit, and making other changes to the tax code to spur new businesses and jobs in the biomedical R&D arena.

Our outreach also included 12 fact sheets and reports showcasing the health and economic benefits of U.S. medical innovation; 40 keynote addresses and presentations given by leadership and staff, driving home the message that medical and health research matters and that current policy making places it at risk; and a dozen events focused on topics including the benefits of—and need for—research to combat chronic pain, the dual role of global health research as a source of lifesaving treatments for use around the world and an economic

Strategy aimed at maximizing funding for scientific research, stopping sequestration and promoting private sector medical innovation.

### First Health Investment Report

Research!America's *U.S. Investment in Health Research* report began tracking the total cross-sector expenditures on medical research in 2002. In the years since, the data shows that spending on medical research has not kept pace with spending on health care.



### PARADE Magazine Partnership

In 2003, Research!America partnered with *PARADE* Magazine to showcase polling data on a range of topics: mental health, stem cell research, genetics and personalized medicine, and chronic pain. *PARADE* also featured Research!America's *Your Congress-Your Health* initiative.

driver in the U.S., and the need to connect the dots between anti-innovation federal decision-making now and the corrosive effects on American priorities. We hosted advocacy training sessions across the country and led a meeting between freshmen Members of Congress and National Institutes of Health Director Francis Collins, MD, PhD.

Throughout 2013, Research!America's Save Research campaign, with more than 60 partners, continued to engage policy makers, the public and the media on the counterproductive impact of sequestration and underinvestment in medical and health research. In social media, the campaign's hashtag, #curesnotcuts, remains a rallying point for advocates committed to re-establishing medical innovation as a top national priority.

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Research!America also laid the groundwork for a new voter education campaign, *Ask Your Candidates! Is Medical Progress a Priority?*, an expansion of the organization's



previous, award-winning *Your Candidate-Your Health* initiative. The *Ask Your Candidates!* program will be a major facet of Research!America's advocacy activities in 2014, combining national outreach to voters and candidates with local activities, each designed to equip voters with information about candidates' commitment to accelerating progress against disabling and deadly diseases.

In 2013, there were glimmers of hope that policy makers understood the importance of medical and scientific innovation in addressing our health and fiscal challenges. Moving forward, Research!America is committed to ensuring a fertile environment which further accelerates innovation, thereby improving the health and prosperity of all Americans.

## Rally for Medical Research

**Research!America joined the lead organization,** American Association for Cancer Research, and a host of other partners for the Rally for Medical Research, aimed at bringing attention to the devastating effect of sequestration of federally funded medical research. The opening event, an April rally in downtown Washington, DC, brought together thousands of scientists, patient advocates and stakeholders. President Barack Obama sent along a message of support, and Members of Congress from both parties and both chambers either spoke at or otherwise supported the event.

“The job of Congress is to choose national priorities going forward and put resources behind them.”

The two-hour program closed with remarks from Research!America’s chair, The Honorable John Edward Porter.

“It’s time for [policy makers] to step up and have the courage to do their jobs,” Porter told the crowd. “The job of Congress — appropriators, leadership, every Member — is to choose national priorities going forward and put national resources behind them... These are people that are accountable to you... If you can’t get

involved and get passionate about what medical research means to our country and our future, who can?”

The event didn’t end there. Rally for Medical Research also sponsored a congressional reception and Capitol Hill day in September; researchers from across the country fanned out to talk to Members of Congress about the importance of funding for the National Institutes of Health and other federal research agencies.

Additional events are planned for 2014.



Research!America’s chair, The Honorable John Edward Porter, speaks at the Rally for Medical Research in Washington, DC.

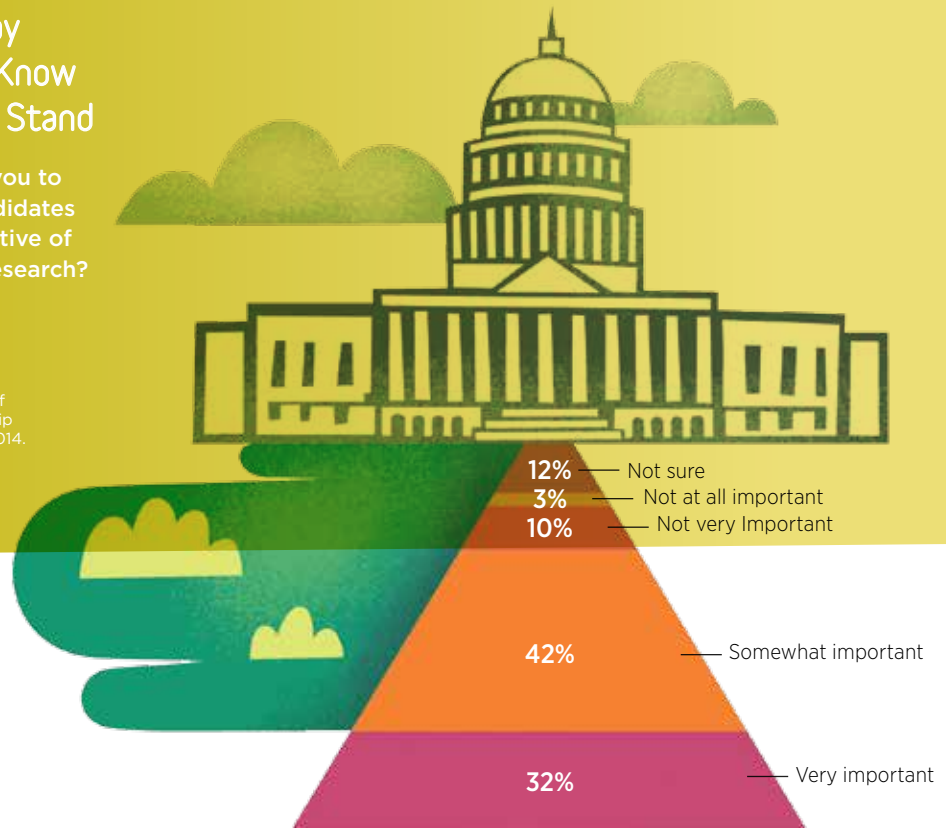
### Save Research Campaign

Facing sequestration and continued budget cuts for federally funded research, Research!America and more than 140 partners launched the Save Research campaign in 2012 to bring attention to these cuts. Through social media, we demanded #curesnotcuts!

## Three-Quarters Say It's Important to Know Where Candidates Stand

How important is it for you to know whether your candidates for Congress are supportive of scientific and medical research?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014.



## Advocacy Academy

In September, Research!America — with support from Pfizer — brought 12 young researchers to Washington, DC, for a two-day Advocacy Academy. The researchers, who came from all corners of the country, were introduced to science policy and effective communications and met with Members of Congress.

During the second day, the scientists applied what they'd learned with a series of meetings on Capitol Hill. Splitting into four groups, the scientists spoke with the offices of Sens. Barbara Mikulski (D-MD), Patty Murray (D-WA), Bob Casey (D-PA), Dan Coats (R-IN), Rob Portman (R-OH), Jeff Flake (R-AZ) and Ted Cruz (R-TX), along with House Minority Leader Nancy Pelosi (D-CA) and Rep. Chaka Fattah (D-PA). After the conclusion of the Hill meetings, the scientists attended Research!America's National Health Research Forum.

Participants were encouraged to send thank-you notes to the Members they met with and write an op-ed that promotes advocacy for research on the participants' campuses.

During dinner — which featured remarks from Research!America Chair John Porter and President and CEO Mary Woolley — and a session on scientific publishing, the scientists were joined by the research fellows from the American Association of Colleges of Pharmacy, who participated in a Research!America advocacy training session.

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## CPH Foundation

Throughout 2013, The CPH Foundation kept public health and the Centers for Disease Control and Prevention in the spotlight. The foundation's alerts, graphics and illustrations helped tell the story of senseless cuts to the CDC budget, as well as the equally troubling cuts to public health and prevention efforts at the state and local levels. CPHF also worked to highlight how cuts hampered disease control and prevention efforts through its blog and other social media.

The CPH Foundation led efforts to overturn funding cuts — generating a letter to Congress early in the appropriations process from 30 nationally recognized health leaders. CPHF also held congressional briefings and led a congressional tour of the CDC's

Atlanta headquarters in November. Attendees included Reps. Tom Price (R-GA), Andy Harris, MD (R-MD) and Michelle Lujan Grisham (D-NM), as well as the deputy chief of staff for House Labor-H appropriations subcommittee Chairman Rep. Jack Kingston (R-GA). During the tour, the attendees met with senior CDC leadership, including CDC Director Tom Frieden, MD, MPH.



The winners of the 2013 Unsung Heroes of Public Health were Anne Saker (left); Julie Wallace, MPH; and Jim Krieger, MD, MPH.

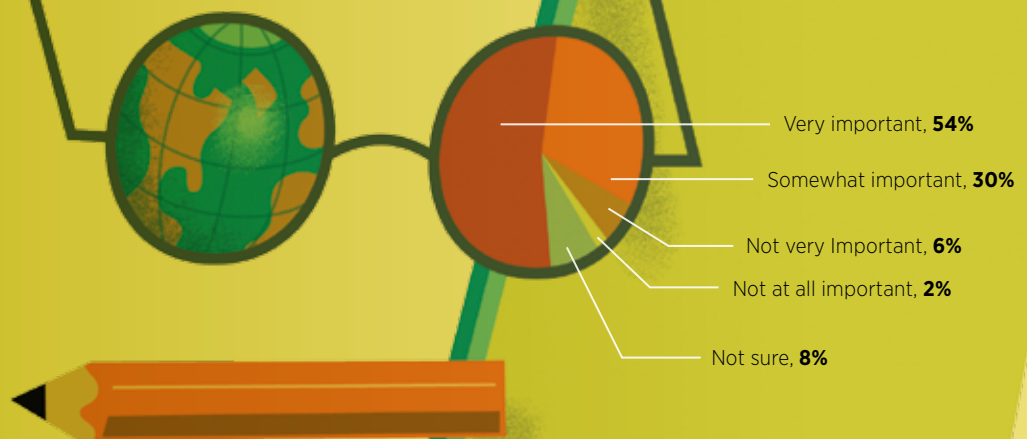
For the fourth year, The CPH Foundation honored its Unsung Heroes of Public Health. Sponsored by AbbVie, the 2013 winners include Jim Krieger, MD, MPH, of Seattle and King County Public Health; Anne Saker, of WCPO Digital in Cincinnati; and Julie Wallace, MPH, of the U.S. Agency for International

Development. Josephine Disparti was recognized with an honorable mention for her efforts to combat health inequality as a member, in 1964, of the Medical Committee for Human Rights. More than 100 attendees joined CPHF on Capitol Hill to applaud these 2013 awardees at a reception sponsored by honorary co-chairs Reps. Lucille Roybal-Allard (D-CA), Jim McGovern (D-MA), Bill Cassidy, MD (R-LA) and Phil Roe, MD (R-TN). Rep. Jim McDermott (D-WA) gave a rousing speech about the value of public health.

### Wide Majority Say It's Important for America to Lead in Research

How important do you think it is that the U.S. is a global leader in medical, health and scientific research?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.





## First Use of Polling to Inform Advocacy for Research

In 1992, Research!America surveyed Maryland residents on issues related to medical and health research — the first of numerous polls to gauge American concern about science, competitiveness, STEM education and a host of other topics.



## Public Health Thank You Day

**Each November, on the Monday before Thanksgiving,** Research!America and our partners pause to thank public health workers across the country. In 2013, Public Health Thank You Day was held November 25, and the message spread across the country — and even beyond it.

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

The initiative wasn't limited to new media, either. Letters to the editor and op-eds appeared in the *York (PA) Daily Record*; the *Globe Gazette* of Mason City, IA; and Beaufort County (NC) Now. The health department in Vanderburgh County, IN, held a health fair in conjunction with Public Health Thank You Day.

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

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## Global Health Advocacy

A disease threat in one country is a disease threat everywhere. Since 2006, Research!America has advocated for global health research and development because discoveries made here aid the American economy and, increasingly, Americans' health.



## Global Health

**Throughout 2013, Research!America made the case** for increased funding and a more conducive policy environment for global health research and development.

One of those events focused on Louisiana. The health and economic impact of neglected tropical diseases — and the critical need for research on NTDs — were showcased during a May forum in New Orleans at the Tulane University School of Public Health and Tropical Medicine. Insects that have the capacity to transmit dengue fever and Chagas disease are increasingly common in Louisiana; but because of the increased demand for air travel, Louisiana is not the only state threatened by those diseases.

NTDs were the focus of a June briefing on Capitol Hill that was sponsored by Reps. Lucille Roybal-Allard (D-CA) and Karen Bass (D-CA) hosted in partnership with Drugs for Neglected Diseases initiative, Global Health Technologies Coalition, The American Society for Tropical Medicine and Hygiene, and Doctors Without Borders/Médecins Sans Frontières. The panelists agreed on several policy priorities: scaling up implementation programs, investing in R&D to develop new tools, and better coordinating the international fight against NTDs.

In November, Research!America cosponsored an event on Chagas disease with the Sabin Vaccine Institute, the National School of Tropical Medicine at the Baylor College of Medicine, the Pan American Health Organization, DNDi, ASTMH and MSF. The discussion focused on the current and future landscape of the treatment of Chagas, the leading parasitic killer in the Americas.



Pierre Beukens, MD, PhD, dean of the Tulane University School of Public Health and Tropical Medicine, provided remarks for Research!America's global health event in New Orleans.

## Pain Forum

**Chronic pain and prescription drug abuse are both growing** public health threats; research into both areas can help identify strategies to prevent them from becoming epidemics.

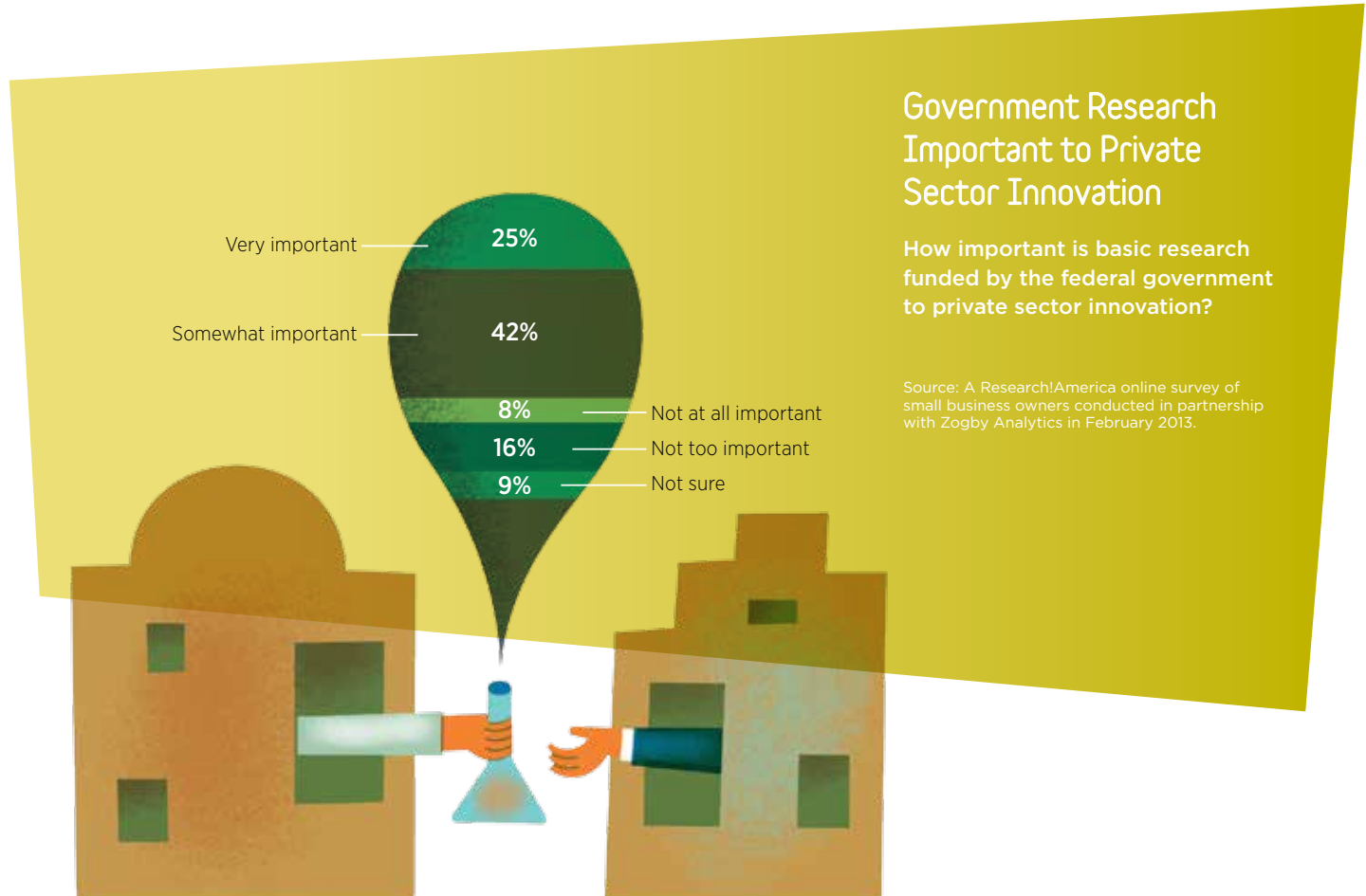
With that in mind, Research!America held a forum to address policy choices that could ease the burdens caused by chronic pain and prescription drug abuse. The event coincided with a release of polling data, commissioned by Research!America, on those same topics.

Research!America Board member Susan Dentzer, senior policy adviser to the Robert Wood Johnson Foundation, moderated a panel that included former Congressman Asa Hutchinson; Douglas Throckmorton, MD, of the Food and Drug Administration; Story Landis, PhD, of National Institutes of Health; Paul Gileno of the U.S. Pain Foundation; Carmen R. Green, MD, of the University of Michigan; and Rebecca Kirch, JD, of the American Cancer Society.

Two areas of need were identified by the panel: non-addictive pain medication and non-medication pain management strategies. Earlier interventions, better awareness of multidisciplinary pain management strategies by health care professionals, and challenges in obtaining health insurance coverage could also help turn the tide on these public health crises.

The panel also discussed ways to lessen the gaps in public education and awareness concerning chronic pain and prescription drug abuse.

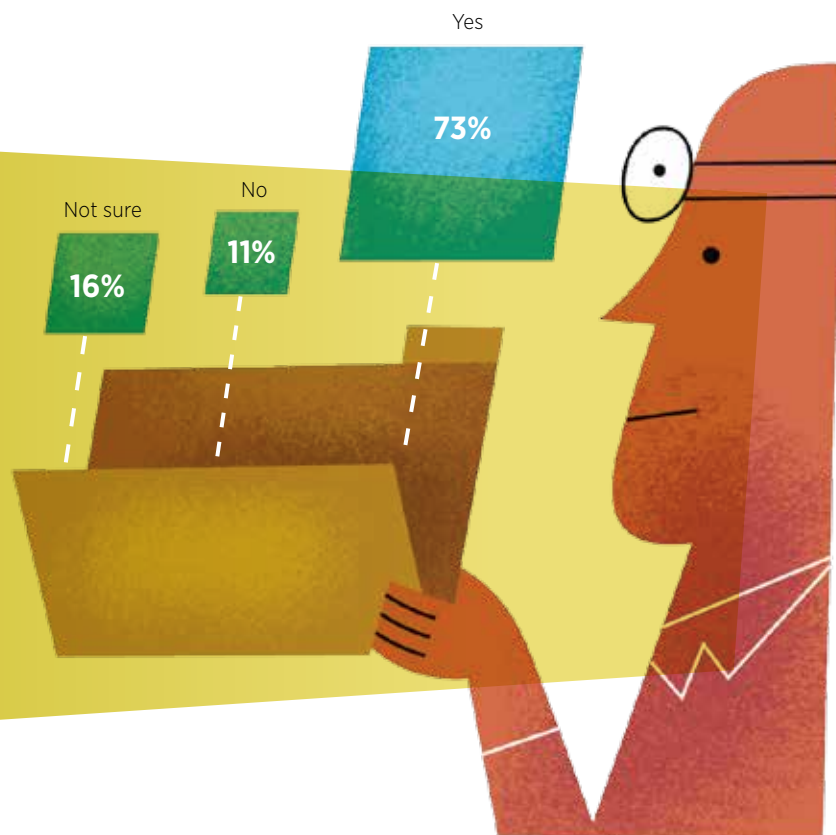
Two areas of need were identified: non-addictive pain medication and non-medication pain management strategies.



## Patients Willing to Share Health Information to Advance Medical Research

Please indicate your willingness to share your personal health information to advance medical research, assuming that appropriate privacy protections are in place.

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.



## Clinical Trials Polling

**In June, Research!America partnered with the** Association of Clinical Research Organizations, the Clinical Research Forum, the Friends of the National Library of Medicine and the Clinical Trials Transformation Initiative to survey the American public's attitude toward clinical trials.

The poll found a disconnect in that nearly three-quarters said they would likely participate in a clinical trial if recommended by their doctor, but less than a quarter said a doctor or other health care professional had ever talked to them about medical research. There was also a disconnect between those who had heard of clinical trials (80%) and those who had participated in them (17%).

Among the reasons many respondents believe individuals don't participate in clinical trials—lack of awareness and a lack of trust.

In July, a second set of polling data was released; it examined attitudes among minorities as they related to clinical trials. Forty-seven percent of Non-Hispanic whites, for instance, said it was important to volunteer for clinical trials to improve the health of others, compared to 61% of African-Americans, 57% of Hispanics and 50% of Asians.

Participation rates showed little difference among races, however. Only 17% of Hispanics, 15% of African-Americans, 15% of non-Hispanic whites and 11% of Asians said they or a family member had participated in a clinical trial.

The surveys polled the American public's attitude toward clinical trials.

**Research!America was covered extensively in broadcast,** print and online media outlets about key issues and events including sequestration, budget negotiations, the National Health Research Forum, Research!America public opinion polls and Public Health Thank You Day. Among the highlights:

- Research!America Chair, former Rep. John Edward Porter (R-IL) and Research!America Board member and former Rep. Kweisi Mfume (D-MD) explained how sequestration can result in a bleak outcome for medical research and innovation in an op-ed in *Roll Call*.
- Porter also penned an op-ed for CNN.com titled, “A do-nothing Congress isn’t healthy.”
- McClatchy-Tribune published an op-ed by Porter in newspapers across the country highlighting the dangers of indiscriminate budget cuts to our medical and health research ecosystem.
- An op-ed by Research!America President and CEO Mary Woolley in *The Scientist* stressed the need for scientists to play a role in winning the hearts and minds of voters by making a personal connection.
- Porter appeared on Comcast Newsmakers, which airs on CNN Headline News, to discuss the impact of spending cuts to research. Woolley discussed the fallout of sequestration to science on the nationally syndicated NPR program *The Diane Rehm Show*, on NPR’s *Marketplace* and as a guest on the Al-Jazeera America network.
- In a letter to the editor in *The New York Times*, Woolley emphasized the necessity of investing in research for health to maintain the nation’s global competitiveness.
- Woolley wrote a letter to the editor of *The Philadelphia Inquirer* urging elected officials to demonstrate attention and support for medical research.
- Woolley was interviewed on numerous regional talk radio stations across the country about the impact of sequestration during the 2013 congressional recesses.

In coordination with our members and partners, messages about the value of medical innovation went viral on social media, significantly increasing Research!America’s presence on Twitter, Facebook and other digital platforms.

Op-eds focused on the dangers of budget cuts to our research ecosystem.

### Dr. Koop Ad Campaign

Former Surgeon General C. Everett Koop, MD, ScD, teamed with Research!America in 1994 for a national campaign on the importance of medical research. Its theme, insufficient medical research can be hazardous to your health, remains just as true today.

## Research Matters Communications Workshop

**At the Research Matters Communications Workshop**, held in early October on the campus of George Washington University, early-career researchers learned how to communicate with the public, the media and policy makers. The event, sponsored by the Society for Neuroscience, Elsevier, Cold Spring Harbor Laboratory and GWU, brought together experts in a number of fields to discuss the art of communication and field questions.

Christie Nicholson, a lecturer at the Alan Alda Center for Communicating Science at Stony Brook University, was the plenary speaker. She stressed the importance of understanding the audience, as well as the critical role that emotion can play in delivering a well-received message.

Two panels followed Nicholson. The first focused on communications with the media and was led by Frank Sesno, director of GWU's School of Media and Public Affairs and a former anchor for CNN. He was joined by reporters and writers from new and old media alike. The second panel discussed communications with policy makers and was led by Debra R. Lappin, JD, principal at FaegreBD Consulting and a Research!America Board member. The panel consisted of four former congressional staffers.

After a lunch, the program concluded with some attendees visiting Capitol Hill and hearing remarks by Rep. Rush Holt, PhD (D-NJ) and Rep. Kevin Yoder (R-KS).



Rep. Rush Holt, PhD (D-NJ), speaks to the attendees of the Capitol Hill session of the Research Matters Communications Workshop. Rep. Kevin Yoder (R-KS) also spoke to the group.

Christie Nicholson stressed the importance that emotion can play in delivering a well-received message.

The other portion of the group stayed at GWU for a presentation by Yevgeniya Nusinovich, MD, PhD, an associate editor with *Science Translational Medicine*, who dispensed tips on submitting publications to research journals.



### NIH Doubling

Research!America was a key leader in doubling the budget for the National Institutes of Health, which was completed in 2003. "Doubling the NIH budget was not possible without Research!America," said House Minority Leader Nancy Pelosi (D-CA).

## National Health Research Forum

**Research!America's 2013 National Health Research Forum**, held in September, promised straight talk and delivered. The event, titled "Straight Talk about the Future of Medical and Health Research," brought together experts from across sectors to discuss the landscape of the American research enterprise — and what lies ahead. Lilly was lead sponsor of the event, which delved into the impact of sequestration on research, public-private partnerships and changes within the regulatory system.

The first panel, focusing on medical research and development, was moderated by journalist Eleanor Clift of *Newsweek* and the *Daily Beast*. It featured John Crowley, president and CEO of Amicus Therapeutics and a patient advocate; William Hait, MD, PhD, global head of R&D at Janssen Pharmaceuticals and a Research!America Board member; Margaret Hamburg, MD, commissioner of the Food and Drug Administration; and Bart Peterson, JD, senior vice president of corporate affairs and communications at Lilly. The discussion centered on innovation within the pharmaceutical industry and the relationship between companies and regulators.

The event brought together experts to discuss the landscape of the American research enterprise — and what lies ahead.

The second panel, which focused on tackling persistent public health challenges, was moderated by Michelle Miller, CBS News correspondent. Panelists were Patrick Conway, MD, chief medical officer of the Centers for Medicare & Medicaid Services; Tom Frieden, MD, MPH, director of the Centers for Disease Control and Prevention; Jay Gershon, DDS, PhD, president of Northeast Ohio Medical University; Foti Panagakos, DMD, PhD, global director of scientific affairs at Colgate-Palmolive; and Lisa Simpson, MB, BCh, MPH, president and CEO of AcademyHealth.

The third panel, which focused on fostering an innovation culture and research as a national priority, was moderated by Norman Ornstein, PhD, resident scholar at the American Enterprise Institute and a contributing editor for *National Journal* and *The Atlantic*. The panelists were Tony Coles, MD, then-chairman and CEO of Onyx Pharmaceuticals; Francis Collins, MD, PhD, director of the National Institutes of Health; Victor Dzau, MD, president and CEO of the Duke University Health System, chancellor for health affairs at Duke University and a Research!America Board member; Robert Hariri, MD, PhD, CEO of Celgene Cellular Therapeutics; and Debra R. Lappin, JD, principal at FaegreBD Consulting, patient advocate and a Research!America Board member.



The final panel of the 2013 National Health Research Forum featured Norman Ornstein, PhD (left); Robert Hariri, MD, PhD; Debra R. Lappin, JD; Francis Collins, MD, PhD; Tony Coles, MD; and Victor Dzau, MD.

## Advocacy Awards

**Visionary leaders in global health, cancer and stem cell research, entrepreneurial development, media and policy** were honored at Research!America's 2013 Advocacy Award Dinner. The awardees were:

✱ EDWIN C. WHITEHEAD AWARD FOR MEDICAL RESEARCH ADVOCACY: **Sens. Richard Burr (R-NC) and Bob Casey (D-PA)**

✱ ISADORE ROSENFELD AWARD FOR IMPACT ON PUBLIC OPINION: **Diane Rehm, author and host of WAMU-FM and NPR's "The Diane Rehm Show"**

✱ RAYMOND AND BEVERLY SACKLER AWARD FOR SUSTAINED NATIONAL LEADERSHIP: **Mark L. Rosenberg, MD, president and CEO of The Task Force for Global Health**

✱ PAUL G. ROGERS DISTINGUISHED ORGANIZATION ADVOCACY AWARD: **California Institute for Regenerative Medicine (CIRM)**

✱ GORDON AND LLURA GUND LEADERSHIP AWARD: **John Crowley, chairman and CEO of Amicus Therapeutics, Inc.**

✱ GEOFFREY BEENE BUILDERS OF SCIENCE AWARD: **John Mendelsohn, MD, director of the Khalifa Institute for Personalized Cancer Therapy at The University of Texas MD Anderson Cancer Center**

The annual Research!America Advocacy Awards program was established in 1996 by the Board of Directors 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.



Top: Advocacy Award winner Diane Rehm poses with Research!America President and CEO Mary Woolley. Above: Secretary of Health and Human Services Kathleen Sebelius, center, talks with Research!America Board members Jackie Lovelace Johnson and Elias Zerhouni, MD.



From left to right, National Institutes of Health Director Francis Collins, MD, PhD, and his wife, Diane Baker, pose with Research!America Board member Jay Gershen, DDS, PhD, and Rep. Marcia Fudge (D-OH).



Left: Advocacy Award winner John Crowley, right, poses with National Center for Advancing Translational Sciences Director Christopher Austin, MD, and Research!America Board member Debra R. Lappin, JD. Right: Sen. Bob Casey (D-PA); Harvey Lodish, PhD; Sen. Richard Burr (R-NC); and Research!America Board member Victor Dzau, MD, pose for a photo. Burr and Casey won the 2013 Edwin C. Whitehead Award for Medical Research Advocacy.



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