## DEVELOPMENT



DELIVERY

HEALTHY AND HAPYY

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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 data, advocacy programs and publications reach the public and decision makers to help advance medical, health and scientific research.

RESEARCH
AMER CA
AN ALLIANCE FOR DISCOVERIES IN HEALTH*

## Elevating Research and Innovation in the Mational Conversation

## Reflecting back on the past year, the research community took heart with

new efforts to advance medical progress such as the 21st Century Cures initiative which aims to speed discovery, development and delivery of lifesaving treatments to patients. Public health responded on the ground to the devastating Ebola outbreak which claimed thousands of lives; and researchers in the public and private sector rushed to develop treatments, a vaccine and innovative measures to help prevent another epidemic. It became all too apparent that years of underinvestment in research were holding us back in preventing an escalating toll from Alzheimer's and many cancers, among other health challenges. Throughout the year, Research!America worked to raise awareness of the importance of sustained, robust funding for the work supported by our federal research agencies, and we worked to advance policies to remove barriers to private sector innovation.

Our Ask Your Candidates! national voter education initiative engaged voters all around the country for the midterm elections and generated statements on research and innovation from congressional candidates, providing background information for advocates as they work with the new Congress. Our award-winning opinion editorials and other publications, as well as extensive social media outreach, were some of the additional ways we captured the attention of the public, media and policymakers.

In 2015, we will build on the hard work of the past year, a year when the foundations of a multi-year advocacy campaign were put in place. With a small group of science and policy leaders, we conceptualized a Blue Ribbon Commission (BRC), to be mandated by Congress and managed by the National Academy of Sciences, to examine the present state of scientific repute in America and present recommendations back to the Congress. We are proud to report that the BRC was included in the FY15 Cromnibus legislation. This is the first time of which we are aware that Congress has asked for such a report; given the flurry of proposed and already-introduced legislation in the new Congress aimed at advancing medical progress, we think the timing is ideal. It is an important step in addressing anti-science sentiment and science illiteracy in a way that is designed to truly engage the American public and ultimately, our elected officials.

As the Commission undertakes its work, Research!America is standing up the Task Force on Science and the Public to formulate a strategy for engaging the public in dialogue and ultimately, heighten appreciation of and support for science as a path to realizing a robust commitment to science that will empower our nation to more fully capitalize on the power of research and innovation to improve the human condition.

The ongoing engagement and support of our members and partners enable Research!America to have a strong impact on public policy. We thank you for standing with us, shoulder to shoulder, on the front lines in 2014 and into the new year, working to ensure strong funding and a globally competitive policy environment for research and innovation. As we move forward, we will recalibrate and recharge our message of the need for finding and delivering lifesaving treatments and cures more efficiently, and more rapidly, in order to intensify the impact that a truly 21st century research and innovation ecosystem can have on the health and economic strength of our country.


The Honorable John Edward Porter Chair

## Manylevalley

President and CEO


The Honorable John Edward Porter Chair


Mary Woolley
President and CEO


## Inajority Agree that Basic Desearch is Critical

Do you agree or disagree with the following statement? "Even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government."


Research!America took part in 95 congressional meetings throughout 2014, including visits to the offices of Senate Minority Leader Mitch McConnell (R-Ky.), Senate Democratic Whip Dick Durbin (D-III.), Sen. Thad Cochran (R-Miss.), Chairman of the Senate Committee on Health, Education, Labor and Pensions Tom Harkin (D-lowa), House Minority Leader Nancy Pelosi (D-Calif.), Rep. Frank Wolf (R-Va.), and Chairman of the Energy and Commerce Committee Fred Upton (D-Mich.) and Rep. Diana DeGette (D-Colo.), who are leading the 21st Century Cures initiative.

We also issued and signed onto 43 letters and statements to Congress on issues that could either stall or propel medical progress including the need for robust funding for medical and health research, tax and regulatory reform, repealing the medical device tax, strengthening the R\&D tax credit, eliminating sequestration and improving travel restrictions that impact scientists' ability to participate in international conferences.

We also submitted testimony on Ebola funding, making the case that this should supplement, not supplant, the increased funding needed to meet other U.S. priorities in the interconnected research and public health arenas.

Also included in our outreach efforts were 18 fact sheets and more than 30 keynote addresses and speaking engagements by Research!America leadership and staff on the economic, societal and human health benefits of research and innovation. The 14 Action Alerts issued by Research! America to our members and supporters resulted in 5,569 messages sent to Congress and the 13 events, either hosted by or in partnership with us, actively engaged our membership, policymakers and individuals in all sectors of the R\&D community.

## We issued and signed onto 43 letters and statements - Congress on issues that could either stall or propel medical progress.

Throughout the year, we worked closely with Sen. Barbara Mikulski (D-Md.), Sen. Tom Harkin (D-lowa), Rep. Chaka Fattah (D-Pa.) and Rep. Frank Wolf (R-Va.) to ensure the FY15 spending bill approved by Congress included a provision to establish a Blue Ribbon Commission charged with discerning American public opinion on scientific research. The Commission, which is to be managed by the National Academy of Sciences, will provide recommendations for how to improve scientific literacy and enhance scientific regard among Americans.


The challenges and opportunities for advancing cancer research and the prospects for a future where cancers are rendered manageable were the main themes of a panel discussion titled "A World Free from Cancer: A Road Paved with Medical Innovation" led by Research! America and the Pancreatic Cancer Action Network (PanCAN) at the New York Academy of Sciences on Feb. 27, 2014.

Jim Pinkerton, Fox News Channel contributor, facilitated the panel that included Robert Hariri, M.D., chairman, founder and chief scientific officer, Celgene Cellular Therapeutics; Julie Fleshman, J.D., MBA, president and CEO, PanCAN; Laurie MacCaskill, chair, national board of directors, PanCAN; Amy Abernethy, M.D., Ph.D., director, Duke Center for Learning

> There's a critical need for collaboration among all stakekolaters.

Health Care; Clifton Leaf, journalist and author; Frank Lichtenberg, Ph.D., Courtney C. Brown Professor of Business, Columbia University; and (not pictured) Scott Gottlieb, M.D., practicing physician, Stamford Hospital and resident fellow, American Enterprise Institute.

The panelists examined various aspects of cancer research and patient advocacy from a regulatory, policy and clinical standpoint. They spoke of some of the challenges posed by the current clinical trials model and the need to identify faster, less expensive and more efficient pathways for the approval of new therapies. The panelists cited the important role of advocates in fostering medical innovation by raising awareness which generates public and private funding and influences policymakers. The group agreed that there's a critical need for collaboration among all stakeholders - pharma, medicine, academia, government and patient organizations - to accelerate medical progress for cancer research.



Edwin C. Whitehead Award for Medical Research Advocacy was awarded to Representatives Frank Wolf (R-Va.) and Chaka Fattah (D-Pa.) for their exemplary leadership and commitment to advancing health research as a national priority.
(L to R) Rep. Chaka Fattah (D-Pa.); Susan Whitehead; Rep. Frank Wolf ( $R$-Va.)


Raymond and Beverly Sackler Award for Sustained National Leadership was awarded to Reed Tuckson, M.D., managing director of Tuckson Health Connections, for his lifelong commitment to advocating the benefits of evidence-based medicine and sustained investment in research.
(L to R) Cora Marrett, Ph.D; Reed Tuckson, M.D.; Evelyn Tuckson


Isadore Rosenfeld Award for Impact on Public Opinion was presented to award-winning actress Glenn Close, her sister Jessie Close and nephew Calen Pick for their efforts to end the stigmas and misunderstandings surrounding mental illness by co-founding the nonprofit organization, Bring Change 2 Mind.
( L to R) Jessie Close; Calen Pick; Glenn Close


## Gordon and L|ura Gund

Leadership Award was presented
to Kathy Giusti, for advancing the research and treatment of myeloma through the Multiple Myeloma Research Foundation (MMRF).
(L to R) Kathy Giusti; William Hait, M.D., Ph.D


Geoffrey Beene Builders of Science Award was presented to Leroy Hood, M.D., Ph.D., for pioneering the development of instruments that paved the way for successfully mapping the human genome.
( $L$ to R) G. Thompson Hutton, Esq.: Mara Hutton; and Leroy Hood, M.D., Ph.D.


Paul G. Rogers Distinguished Organization Advocacy Award was presented to the Progeria Research Foundation (PRF) for bringing progeria, a rare and fatal pediatric disease, to the forefront of translational research.
( $L$ to R) Audrey Gordon, Esq.;
Leslie Gordon, M.D., Ph.D;
Scott Berns, M. D., MPH efforts have advanced our nation's commitment to research. The impact of these individuals and organizations is recognized as having been notably effective in advancing our nation's commitment to research.

## AACP Research Fellows Workshop

 The American Association of Colleges of Pharmacy (AACP) Research Fellows Science Advocacy and Communications Workshop, hosted by Research! America, was held the morning of the 2014 National Health Research Forum. In its second year, the workshop gives the fellows, both tenured and on a tenure track, an understanding of the advocacy issues surrounding research. Research! America board member Mary Hendrix, Ph.D., president and scientific director of the Stanley Manne Children's Research Institute, was a guest speaker. The 20 workshop participants also attended the Forum and interacted with leaders in research, public health, industry, patient community and academia.Catherine St. Hill, assistant professor and research coordinator, University of Minnesota, spoke at the Forum.

## Americans Say Government

Should Elevate ST ElM Education

Do you agree or disagree the federal government should assign a higher priority to improving education focused on science, technology, engineering and mathematics and careers in those fields?



Research!America's 2014 National Health Research Forum, held in September, brought together a diverse group of panelists from industry, academia, patient groups, research institutes and government for wide-ranging discussions on different facets of the theme "Straight Talk about the Future of Medical and Health Research." There was a particular focus on the findings of Battelle's 2014 Research and Development Funding Forecast, which projects China's investment in R\&D will surpass that of the United States as soon as 2023.

The first panel, the topic of which was "Where will U.S. Research and Development be in 2023?" was moderated by Corby Kummer, senior editor, The Atlantic magazine. It featured France Cordova, Ph.D., director, National Science Foundation; Anthony Fauci, M.D., director, National Institute of Allergy and Infectious Diseases; William Hait, M.D., Ph.D., global head, Janssen Research \& Development; Richard Myers, Ph.D., president, science director, HudsonAlpha Institute for Biotechnology; and John Seffrin, Ph.D., CEO, American Cancer Society. During the discussion, the panelists not only emphasized the importance of increasing R\&D funding, but the value of making science a greater priority in the U.S., including retaining more young scientists, and maintaining America's role as the leader in research and development.

The second panel, which focused on "Code Red Again: Can We End the Assault on Public Health Research and Practice?" was moderated by Lori Montenegro, national correspondent, Telemundo. Panelists included Georges Benjamin, M.D., executive director, American Public Health Association; Tom Frieden, M.D., MPH, director, Centers for Disease Control and Prevention; Lynn Goldman, M.D., M.S., MPH, dean, Milken Institute School of Public Health, The George Washington University; Richard Kronick, Ph.D., director, Agency for Healthcare Research and Quality; and Jack Natters, M.D., vice president, external medical affairs, Pfizer Inc. The panel discussion covered current threats to health research and practice, including the Ebola outbreak, the need to educate policymakers on the essential role of the public health system, and the value of investing in science and health research.

The third panel, moderated by Margot Sanger-Katz, health care correspondent, The New York Times, The Upshot, focused on the topic "What's Right - and Wrong - With the Research Ecosystem?" and discussed what must be done to improve the discovery and development of new treatments and therapies primarily through the regulatory process. The panelists were Pablo Cagnoni, M.D., president, Onyx Pharmaceuticals, Inc.; Robert Hugin, chairman and CEO, Celgene Corporation; E. Albert Reece, M.D., Ph.D., MBA, dean, University of Maryland, School of Medicine; and Janet Woodcock, M.D., director, Center for Drug Evaluation and Research, Food and Drug Administration.


# ExE AD NBM Restract remorabie ovicisem 

A roundtable discussion on "The Public's Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease," was hosted by Research!America at the National Press Club in Washington, D.C., in September. Attended by members of the media and leaders in the eye and vision research community, a panel of experts took an in-depth look at data from a national public opinion poll commissioned by Reasearch!America and the Alliance for Eye and Vision Research (AEVR), and supported by Research to Prevent Blindness, which revealed different perspectives among racial and ethnic groups about eye and vision health.

Prior to the panel discussion, James Jorkasky, executive director, AEVR, provided an overview of the poll which is considered to be the most rigorous study of minority populations and their attitudes toward vision and vision loss to date. The panel was moderated by Michelle Miller, CBS News correspondent, and panelists included Neil Bressler, M.D., chief of the retina division, Wilmer Eye Institutes at Johns Hopkins University School of Medicine; Paul Sieving, M.D., Ph.D.
director, National Eye Institutes; Karla Zadnik, O.D., Ph.D., dean, The Ohio State University College of Optometry; and James Tsai, M.D., president, New York Eye and Ear Infirmary of Mount Sinai. The panelists covered a variety of topics pertaining to the poll findings: the consequences of decreased federal funding, including the loss of human capital, and the importance of educating Congress and the general public about eye health, in particular that newer treatments can reduce the cost and prevalence of eye disease over time.

> The poll is considered to be the most rigorous study of minority populations and their attitudes toward vision and vision loss to date.
(Right to left) Moderator Michelle Miller; James Tsai, M.D.; Karla Zadnick, O.D., Ph.D.; Paul Sieving, M.D., Ph.D.; and Neil Bresster, M.D.


## Pally for iredical Pesceareh

At the September 2014 Rally for Medical Research Hill Day, of which Research! America was a sponsor, 300 different groups representing the medical research community joined together in Washington, D.C., to provide a united effort to urge Congress to make funding for the National Institutes of Health (NIH) a higher national priority.

Following a reception the previous evening at the Kennedy Caucus Room - Celebrating the Science Supported by the NIH - representatives from these groups met with both the Senate and House offices of 40 different states, including more than 100 meetings directly with members of Congress, to raise awareness of the urgent need for an increased investment in the NIH. Research! America staff escorted a small group of advocates from

Fruding for the KI H should be a higher national New Jersey to five different meetings, three of which were with members of Congress representing New Jersey: Sen. Cory Booker (D-N.J.), Rep. Rush Holt (D-N.J.) and Rep. Scott Garrett (R-N.J.). They also met with staff from the offices of Sen. Robert Menendez (D-N.J.) and Rep. Frank Pallone (D-N.J.).
(Left to right) Jayme Hennenfent,
Research! America science policy fellow, Lori Covey, professor, Rutgers University: Senator Cory Booker (D-N.J.); Jenny Luray, director, public policy and government relations, BD; and Kathleen Mewhiney, president, The John and Amy Mewhiney Cancer Foundation.


## Important for

 Elected Officials to Listen to ScientistsHow important is it that elected officials at all levels listen to advice from scientists?


Research!America's national voter education initiative - Ask Your Candidates! Is Medical Progress a Priority? - launched in early 2014 for the midterm elections, not only helped educate voters on the position of congressional candidates regarding their support for medical and health research, but also urged voters to convey the personal impact of medical innovation to candidates to ensure that policy decisions reflect the needs of American citizens.


After eight months of engagement with voters and candidates, Ask Your Candidates! culminated with Research!America's PostElection Briefing. Held just two days after the midterm elections in November, esteemed Research!America board members and partners, former congressmen, and other leaders and stakeholders in the medical research community gathered at the American Association for the Advancement of Science (AAAS) for panel discussions. Research!America President and CEO Mary Woolley presented findings from Ask Your Candidates!, which, due in part to efforts of national partner organizations, volunteers, advertising and social media, collected nearly 170 responses from Democratic, Republican and third-party candidates, including 55 statements from winning candidates. The findings from the initiative helped set the tone for a discussion about advocacy efforts moving forward.

Following an overview of the election results by political analyst David Hawkings, senior editor, CQ Roll Call, the first panel discussed what America could expect from the new Congress in terms of support for medical research. Opinions were mixed about federal funding for research but panelists believed there might be an opportunity to make the R\&D tax credit permanent in the new Congress. The panel was comprised of moderator Rebecca Adams, associate editor, CQ Healthbeat; the Hon. John E. Porter, Research!America Chair; the Hon. Mike Castle, Research!America Vice Chair; the Hon. Kweisi Mfume, Research!America board member; and the Hon. Bart Gordon.

(Left to right) Moderator Rebecca Adams, the Hon. John E. Porter; the Hon. Kweisi Mfume, the Hon. Mike Castle and the Hon. Bart Gordon.

The event culminated with a discussion focused on next steps for advocates to engage the new Congress with Research!America partners Bill Andresen, associate vice president, federal affairs, University of Pennsylvania; Brent Del Monte, vice president, federal government relations, Biotechnology Industry Organization (BIO); Sue Nelson, vice president, federal advocacy, American Heart Association; and Ted Thompson, CEO, Parkinson's Action Network.

## Deception for hew inembers of Congress

Research!America co-sponsored a New Members Event during orientation week for newly-elected members of Congress in November, hosted by The Hill newspaper at the National Postal Museum in Washington, D.C. Mary Woolley, Research!America president and CEO, and Research!America board member Alan Leshner, Ph.D., CEO, American Association for the Advancement of Science, were joined by Tom Frieden, M.D., MPH, director, Centers for Disease Control and Prevention (CDC) at the event which attracted new, current and former members of Congress and congressional staffers, including House Energy and Commerce Committee Chairman Fred Upton (R-Mich.), Reps. Chris Van Hollen (D-Md.), ranking member of the House Budget Committee, Jeb Hensarling (R-Texas), and Rep.-elect Ryan Costello (R-Pa.), Rep.-elect Brian Babin (R-Texas) among others.

Remarks were provided by Reps. Upton and Van Hollen, and former Rep. John Shadegg (R-Ariz.) to help new members become acclimated on Capitol Hill and work in a bipartisan fashion. Newly-elected members were also encouraged to visit medical research institutions in their districts and states to learn more about innovative studies that could potentially advance the treatment and prevention of disease and spur economic growth.


On the Monday before Thanksgiving, Research!America joined other public health organizations and advocates to celebrate Public Health Thank You Day, a chance to recognize public health professionals who work round-the-clock to protect the health of all Americans. In particular, Research!America highlighted several early-career professionals preparing to face future challenges in their fields. As the Ebola and Enterovirus outbreaks prompted swift action and strategic planning of public health professionals to contain the diseases, the 2014 Public Health Thank You Day saw unprecedented success and participation, with the support of a dozen partner organizations, the Acting U.S. surgeon general and Tom Frieden, M.D., MPH, director, Centers for Disease Control and Prevention (CDC). Partners included the American Association of Colleges of Nursing, the American Public Health Association, the Society for Public Health Education, the University of North Carolina Gillings School of Global Public Health, the Johns Hopkins University Bloomberg School of Public Health, the American Association of Colleges of Pharmacy, the American Cancer Society, the Association of Public Health Laboratories, the American Veterinary Medical Association, The Ohio State University and Susan G. Komen.


2014 PUBLIC HEALTH THANK YOU DAY NOVEMBER 24

Public Health is Your Health

## Americans Willing to Share Personal Health Data for Desearch and Health Care

For which of the following would you be willing to share your personal health information? (Choose all that apply)

## TO ADVANCE MEDCAL RESEACCH: $55 \%$ SO HEALTH CAEE PRONIDERS CAN INRRNE PATEET CARE: $00 \%$

SO PULLC HEALTH OFFCLILS CAN BETTER TRACK DISEASE AND DISABLLITY AND THE CAMEES: $46 \%$ NOWE: 10\%
NOT SRE: $13 \%$

## CAMPACV FOR WELL C HEALTH FONOATON

The Campaign for Public Health Foundation (CPHF) worked throughout 2014 to ensure that the messages Congress received about the need for funding to support the Centers for Disease Control and Prevention (CDC), were relevant, accurate and delivered by advocates with a determination to effect change.

> The letter to the President supported the Administration's emergency funding request to tight Ebola.

With the support of sponsors like Research!America, CPHF hosted an educational tour for a bipartisan delegation of U.S. Senate Committee on Health, Education, Labor and Pensions (HELP) staffers of the CDC headquarters in Atlanta, Ga., in May. During the visit, attendees learned of the many initiatives of the CDC, and met with Tom Frieden, M. D., MPH, director, CDC.

The Foundation sent a letter to President Barack Obama supporting the Administration's Emergency Funding Request to Enhance the U.S. Government's Response to Ebola at Home and Abroad. The letter expressed hope that Congress would allocate funding for the CDC, and when the omnibus spending bill for 2015 was passed, of the $\$ 5.4$ billion in funds to respond to the Ebola crisis, $\$ 1.77$ billion was allocated for the CDC.

The fifth annual CPH Foundation Unsung Heroes of Public Health honored exceptional individuals in their field including Michael Wahl, M.D., FACEP, FACMT, of the Illinois Poison Center in Chicago, III.; Robert L. Burhans, formerly of the New York State Department of Health (NYSDOH), and Catherine C. Slemp, M.D., MPH, formerly of the West Virginia Bureau for Public Health. An honorable mention was awarded to Donna A. Patterson, Ph.D., of Wellsley College, for her coverage of the Ebola outbreak in The Huffington Post.

CPHF staff and a bipartisan group of congressional staffers visit CDC headquarters in Atlanta, Ga .


## MEDA

$\triangleright$ Research!America President and CEO Mary Woolley's commentary on "A Worthy New Year's Resolution for the New Congress" was published in

## THE HUFFINGTON POST

$\triangleright$ Research!America Chair the Hon. John E. Porter and board member the Hon. Kweisi Mfume wrote a joint op-ed published in THE HILL'S CONGRESSIONAL BLOG about the implications of declining budgets at the federal health research agencies.

## $\triangleright$ Woolley's op-ed for THE

hUfFINGTON POST, "Will Medical
Innovation Be an Afterthought This Election Season?" emphasized the need for candidates to share their views on medical and health research during the midterm elections.

## $\triangle$ Regional RADIO AND PRINT

INTERVIEWS with Woolley focused on the Ask Your Candidates! national voter education initiative and the impact of federally funded research in different states.
$\triangleright$ Porter strongly encouraged researchers to engage with policymakers, media and their local communities in the SCIENCE MAGAZINE op-ed, "Time to Speak Up for Research."

D Woolley discussed the ALS ice bucket challenge as a guest on BioCentury TV and with THE WASHINGTON POST and other publications.
$\triangleright$ Ellie Dehoney, Research!America vice president of policy and advocacy, was quoted in CQ ROLL CALL about President Obama's emergency funding request to combat Ebola.

Research!America received considerable media attention in 2014 with compelling interviews and commentary on key topics related to the midterm elections, medical innovation, current and emerging health threats, national public opinion polling, the National Health Research Forum and the Advocacy Awards Dinner. Among the highlights:
$\triangle$ Research!America board member Nancy Brown, CEO of the American Heart Association and Chair Porter, published a joint op-ed in THE HUFFINGTON POST about the human health and economic benefits of federally funded research.
$\triangleright$ Woolley and Research!America board member, Alan Leshner, Ph.D., CEO of the American Association for the Advancement of Science (AAAS) penned a lead editorial in SCIENCE MAGAZINE calling on scientists to cultivate relationships with new members of Congress.


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