Research!America Announces 2014 Advocacy Award Winners

Actress Glenn Close and her family; Leroy Hood, MD, PhD, president of the Institute for Systems Biology; Kathy Giusti, founder and CEO of the Multiple Myeloma Research Foundation; Reed Tuckson, MD, managing director of Tuckson Health Connections; and The Progeria Research Foundation (PRF) will be among those honored at Research!America’s 18th annual Advocacy Awards. The event will be held March 12, 2014, at the Andrew W. Mellon Auditorium in Washington, DC, as a part of Research!America’s 25th anniversary commemoration.

Close, the award-winning actress—along with her sister, Jessie, and nephew, Calen—will receive the 2014 Isadore Rosenfeld Award for Impact on Public Opinion. Urged by her sister and nephew living with mental illness, Close co-founded Bring Change 2 Mind, a not-for-profit organization dedicated to ending the stigmas and misunderstandings surrounding mental illness. Together, the Close family shares an inspiring message of recovery, managing illness and leading a productive life.

Hood will receive the 2014 Geoffrey Beene Builders of Science Award for pioneering the development of instruments that paved the way for the successful mapping of the human genome. He was one of a small number of early and persistent advocates for the Human Genome Project. Continued on page 5

Sequestration Likely to be a Key Topic for Budget Conference Committee

As part of the terms of the agreement to end the federal government shutdown and increase the nation’s debt ceiling, a bipartisan, bicameral committee was formed to bridge gaps in spending philosophies between the House and Senate.

The group of 29—led by Senate Budget Committee Chair Patty Murray (D-WA), Senate Budget Committee Ranking Member Jeff Sessions (R-AL), Continued on page 4

Patients Willing to Share Health Information for a Variety of Reasons

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>So researchers can better understand diseases and develop new ways to prevent, treat and care for them</td>
<td>74%</td>
<td>12%</td>
<td>14%</td>
</tr>
<tr>
<td>To advance medical research</td>
<td>73%</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>So health care providers can improve patient care</td>
<td>72%</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>So public health officials can better track disease and disability and the causes</td>
<td>67%</td>
<td>17%</td>
<td>17%</td>
</tr>
</tbody>
</table>

SOURCE: A RESEARCH!AMERICA POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN MAY 2013. (DUE TO ROUNDING, TOTALS DO NOT ADD TO 100%.)
Members TAKE Action

PANCREATIC CANCER ACTION NETWORK

When the Pancreatic Cancer Action Network was founded in 1999, the 5-year relative survival rate was 5.3%, according to National Cancer Institute statistics. In the intervening years, the survival rate has remained stubbornly low. What is different is awareness: Today, more research is being conducted by more scientists, and the pancreatic cancer advocacy community has never been bigger. So too for Manhattan Beach, CA-based Pancreatic Cancer Action Network, which hired its first employee in 2000 and will soon hire its 100th.

President and CEO Julie Fleshman, JD—who was that first employee—can explain just how far the science around pancreatic cancer has come. Tumors tend to be surrounded by, in Fleshman’s words, a dense microenvironment that makes drug delivery difficult; it’s one of many reasons why treating pancreatic cancer is so challenging.

“That finding … is something we’ve only started to appreciate the significance of in the last five years,” Fleshman, who lost her father to pancreatic cancer in 1999, said. “It shows you that when you finally dedicate time and resources and people to a topic, you start to understand what the challenges are, which then allows people to focus their efforts in the right way to make scientific advancements.”

And the Pancreatic Cancer Action Network sees those advances are coming. Early in 2011, the organization announced an initiative to double the survival by 2020; now, seven years out, Fleshman said reaching the goal will be difficult but far from impossible. Even so, the future holds promise for patients. There are 142 active clinical trials, according to the organization’s comprehensive pancreatic cancer clinical trials database. Moreover, earlier-stage research is ongoing and being taken up by an ever greater number of scientists.

“That’s probably the most significant change,” Fleshman said. “We’re learning more about the disease, we’re understanding better the challenges about why it is so difficult to treat, and that is going to get us to changing patient outcomes in the future.”

And because research is such a critical part of the puzzle, Fleshman said it’s important for the organization to be a Research!America member.

“Biomedical research is a key priority for our organization,” she said. “With pancreatic cancer, there is no detection tool, and we need better treatment options. We’re not going to make those scientific advances unless there is more federal funding for the disease. We’re very proud to partner with Research!America to make medical research a national priority.”

Visit www.pancan.org.

Research!America Adds Value FOR OUR MEMBERS

Research!America stands on a reputation of innovative advocacy that generates results serving our mission and the interests of our members:

- Research!America’s Advocacy Awards celebrate the efforts of those who have made a difference in advocating for or increasing awareness of the role of health and medical research.
- Research!America has conducted public opinion polling since 1992, including numerous national surveys and polling in 44 states and the District of Columbia. Our polling asks Americans for their thoughts on research, public health, global health and other topics concerning research to improve health.
Congressional Outreach
InsideHealthPolicy highlighted a letter penned by Research!America President and CEO Mary Woolley urging the congressional Budget Conference Committee to end sequestration and tackle tax and entitlement reform. “Deficit reduction requires smart tax and entitlement reforms—reforms that do not move us one step forward and two steps back by compromising private sector medical innovation,” Woolley wrote.

Recent Senate testimony by Research!America Board member Alan Leshner, PhD, CEO of the American Association for the Advancement of Science, about the impact of the government shutdown to science was highlighted in several outlets, including CNN Money, The Huffington Post and The Washington Post.

Campaign to Fix the Debt
Mary Woolley was among the speakers at a press conference that aired on C-SPAN urging Congress and the president to put in place a long-term agreement to address the national debt. Woolley joined Leon Panetta, former Secretary of Defense, and research advocates Hunter Rawlings, PhD, president of the Association of American Universities, and Ian Kremer, executive director of Leaders Engaged on Alzheimer’s Disease.

Improving Mental Health
The Boston Globe published an op-ed by Research!America Board member Patrick Kennedy, announcing the launch of The Kennedy Forum, which is designed to unite the mental health community and focus on mental health research and treatment. The forum was highlighted by numerous outlets, including USA Today, CBS News and The Huffington Post.

NEOMED Dedication Ceremony
Research!America Board member Jay Gershen, DDS, PhD, president of Northeast Ohio Medical University (NEOMED), was quoted in the Ravenna County (OH) Record-Courier about the university’s 40th anniversary and the two new buildings on its Rootstown, OH, campus. Mary Woolley lauded NEOMED’s successes in research and innovation during her remarks at the dedication ceremony.

Cardiovascular Disease Research Investment
Research!America Board member Nancy Brown, CEO of the American Heart Association, wrote an op-ed for The Huffington Post about “Rylan,” a boy living with cardiovascular disease. Brown says investments in research can lead to “many groundbreaking discoveries that could help Rylan, such as advancements in heart transplantation.”

Government Shuts Down Science
Mary Woolley was interviewed live on Al Jazeera America’s evening news hour, providing specific examples about the lingering effects of the shutdown on science. Politico also quoted Woolley about the shutdown. “Even if the government opens tomorrow, a significant amount of damage has been done,” she said.

The Boston Globe published an op-ed by Research!America Board member Elizabeth Nabel, MD, president of Brigham and Women’s Hospital, describing the impact of sequestration as “not only medically devastating; it is also fiscally and economically shortsighted.”

The latest in last-minute, kick-the-can-down-the-road decision making by our government has little positive to say for it, and the polls show it: Congress is registering record-low approval ratings. It’s enough to discourage any citizen from feeling positive about our nation’s future, much less wanting to pay attention to Washington, which has now set up not one but three cliffhangers: December 13 for a newly appointed Budget Conference Committee to recommend overarching solutions; January 15 for a decision on the current ‘continuing resolution’ that keeps the government open; and February 7 for another debt ceiling decision. As if this weren’t enough, January 15 is also when year two of the “sequester” is scheduled to exact its toll. The sequester, year two, is the next round of a decade of severe, across-the-board cuts to many government-funded priorities.

You may be as discouraged as the rest of the nation when it comes to paying attention to Washington. But if you care about research, it’s more important than ever to get involved. Time is short, and much is at stake; things are going to move quickly and in a way that is difficult to predict. Please stay involved—sign up for our advocacy alerts at http://bit.ly/P9a7p and watch for my weekly letters Thursday afternoons on our blog, researchamerica.wordpress.com—and look to these timely messages for suggestions on steps you can take in a few minutes to influence the future of research and the future of health. So much hangs in the balance; if enough of us speak out, we can change the outcome of things to come.
**Sequestration Topic for Budget Conference Committee**

Continued from page 1

House Budget Committee Chair Paul Ryan (R-WI) and House Budget Committee Ranking Member Chris Van Hollen (D-MD)—has a deadline of December 13 to devise a spending plan. The future of sequestration is expected to be a much-discussed topic in the negotiations.

For stakeholders in medical research, that means the next six weeks are an absolutely crucial time for advocacy. Your elected officials need to hear from you: Sequestration must be at least suspended and, ultimately, eliminated. These arbitrary spending cuts continue to slow innovation, negatively impact public health efforts, and reduce America’s standing as a global leader in innovation.

Instead of eroding research efforts, the Budget Conference Committee—and eventually the full Congress—must fund the federal health agencies at a level sufficient to meet public health needs and capitalize on scientific opportunity. And in doing so, patients, their families and the American economy benefit.

**CPH Foundation Update**

The CPH Foundation’s fourth annual Unsung Heroes of Public Health Awards, supported this year by AbbVie, will close nominations on Public Health Thank You Day, held annually on the Monday before Thanksgiving (November 25, 2013). To help spread awareness of the awards, the foundation has developed social media-friendly banner ads inviting nominations. Partner groups and friends are invited to ‘share’ these banner ads to help us find this year’s Unsung Heroes. More information can be found on our award page, www.cphfoundation.org/annual_awards.html.

CPH is also finalizing travel plans for our next tour of the Centers for Diseases Control and Prevention for Members of Congress. On November 8, members are planning to travel with CPH to Atlanta and will be given a behind-the-scenes look at the agency. They will also meet with CDC leaders to discuss the agency’s work and its challenges. Research!America helped support the tour, as did four other partner organizations.

CPH is also in the process of organizing a hepatitis C briefing on Capitol Hill, in conjunction with our friends on the bipartisan Congressional Study Group on Public Health. The study group is an official organization of congressional members formed shortly after CPHF staff led 19 staff on the first of CPHF’s congressional tours back in 2006.

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**2013 FEDERAL RESEARCH BUDGET**

<table>
<thead>
<tr>
<th>Agency</th>
<th>FY12 Actual</th>
<th>FY13 Post-Sequestration</th>
<th>FY14 Senate’s Request</th>
<th>FY14 President’s Request</th>
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<tr>
<td>National Institutes of Health</td>
<td>$30.7 billion</td>
<td>$29.1 billion</td>
<td>$30.9 billion</td>
<td>$31.0 billion</td>
</tr>
<tr>
<td>Centers for Disease Control and Prevention*</td>
<td>$5.7 billion</td>
<td>$5.4 billion</td>
<td>$5.8 billion</td>
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</tr>
<tr>
<td>Food and Drug Administration</td>
<td>$2.6 billion</td>
<td>$2.5 billion</td>
<td>$2.6 billion</td>
<td>$2.6 billion</td>
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<tr>
<td>National Science Foundation</td>
<td>$7.0 billion</td>
<td>$6.9 billion</td>
<td>$7.4 billion</td>
<td>$7.6 billion</td>
</tr>
<tr>
<td>Agency for Healthcare Research and Quality**</td>
<td>$0.37 billion</td>
<td>$0.35 billion</td>
<td>$0.36 billion</td>
<td>$0.35 billion</td>
</tr>
</tbody>
</table>

* CDC core budget
** Excludes funding from transfers
Research!America Hosts Communications Event for Young Scientists

Research!America’s science communications event, “Research Matters Communications Workshop: Promoting Basic Research in a New Age of Communications: Challenges and Opportunities,” was held October 9 at George Washington University in Washington, DC.

The event consisted of a plenary session on communicating with the public and two panels that explored the viewpoints of the media and policy makers. After lunch, some attendees stayed at GW to learn about tips on submitting publications to research journals. Others traveled to Capitol Hill where—in spite of the government shutdown—they had discussions with Rep. Rush Holt, PhD (D-NJ), Rep. Kevin Yoder (R-KS) and Yoder’s legislative director.

The workshop was sponsored by Research!America, the Society for Neuroscience, Elsevier, Cold Spring Harbor Laboratory and GW.

To read more about the event, visit http://bit.ly/H2aLME.

Nobel Prize Winners in Medicine/Physiology, Chemistry Announced

Six U.S.-based scientists are the recipients of the 2013 Nobel Prizes in chemistry and medicine or physiology, the Royal Swedish Academy of Sciences announced in early October.

James Rothman, PhD, of Yale University; Randy Schekman, PhD, of the University of California, Berkeley; and Thomas Südhof, MD, of Stanford University, won the 2013 Nobel Prize in physiology or medicine. Martin Karplus, PhD, of Harvard University; Michael Levitt, PhD, also of Stanford; and Arieh Warshel, PhD, of the University of Southern California, won the 2013 Nobel Prize in chemistry.

The winners have had extensive research funding from the National Institutes of Health and the National Science Foundation.

Biden, Sebelius Attend Forum on Mental Health Policy

Vice President Joe Biden, Secretary of Health and Human Services Kathleen Sebelius and other celebrities gathered in Boston in late October for The Kennedy Forum to discuss polices that affect people with mental illness, intellectual disabilities and addiction. The forum, which coincided with the 50th anniversary of President John F. Kennedy’s signing of the Community Mental Health Act, was hosted by Research!America’s Board of Directors and Congressman Patrick Kennedy.

2014 Advocacy Award Winners

Continued from page 1

Genome Project. Hood is also credited with the development of the discipline of systems biology, which introduced the revolutionary concept to understand not only each biological network but also how the networks function together.

Tuckson will receive the 2014 Raymond and Beverly Sackler Award for Sustained National Leadership for his lifelong commitment to advocating the benefits of evidence-based medicine to the public and policy makers and for adoption of supporting policies that maintain a strong and sustained investment in research, including health services research. He regularly speaks to the media about the need for continued U.S. investment in research and programmatic funding.

Giusti will receive the 2014 Gordon and Llura Gund Leadership Award for advancing the research and treatment of myeloma, the second most common blood cancer. A myeloma survivor, Giusti co-founded MMRF with her twin sister. The organization established the first myeloma tissue bank and launched an initiative that resulted in the complete mapping of the myeloma genome, which was made publicly available to advance myeloma research.

PRF will receive the 2014 Paul G. Rogers Distinguished Organization Advocacy Award for its role for bringing progeria, a rare and fatal pediatric disease of premature aging, from obscurity to the forefront of successful translational research. The organization also led the discovery of the progeria gene, the identification of a potential drug treatment and, eventually, the first progeria clinical trial. Co-Founder and Medical Director Leslie B. Gordon, MD, PhD, will accept the award on behalf of the organization.

The winner of the Edwin C. Whitehead Award for Medical Research Advocacy will be named by Research!America’s Board of Directors at a later date.
Mark McClellan, MD, PhD, director of the Health Care Innovation and Value Initiative of Brookings Institution and a Research!America Board member, has been appointed to Johnson & Johnson board of directors.

***

Georges C. Benjamin, MD, executive director of the American Public Health Association and a Research!America Board member, has been appointed director designate of the board of directors of Legacy.

***

The National Institutes of Health announced its 2013 high-risk, high-reward grants; 78 awards to support exceptional innovation in biomedical research.

***

Harvey Alter, MD; Daniel Bradley, PhD; Stephen Joseph Elledge, PhD; King Holmes, MD, PhD; James Hogg, MD, PhD; and Sir Gregory Winter, PhD, have been named the 2013 winners of the Canada Gairdner Awards, which honors biomedical researchers from around the world.

Event to Explore New Approaches, Incentives in Drug Development

One Mind, the Ewing Marion Kauffman Foundation and the Duke University School of Law are hosting a forum on new approaches and incentives in drug development. The event will be held at the National Academy of Sciences building in Washington, DC, on November 22.

The program will look at how the current business and legal landscape in drug development has impacted R&D strategies and whether further economic incentives are necessary for biopharmaceutical development. Chris Austin, MD, director of the National Center for Advancing Translational Sciences, will provide the luncheon keynote.

The event is free, but registration is required. Register at http://bit.ly/1ejGheo.

Rep. C.W. Bill Young Dies at 82

Rep. C.W. Bill Young (R-FL), most well known for his work with the military and veterans but also a strong advocate for medical research, died October 19 in Bethesda, MD. He was 82.

Young, who represented Florida for more than four decades, was a key figure in the doubling of the budget for the National Institutes of Health. He and his wife, Beverly, were also responsible for founding the national bone marrow registry program in 1986. In 2001, Bill Young received Research!America’s Edwin C. Whitehead Award for Medical Research Advocacy.

“I was privileged to serve with him on the Appropriations Committee, where he was a leading advocate for biomedical research,” House Minority Leader Nancy Pelosi (D-CA) said in a statement. “Chairman Young’s work to create a national registry for bone marrow donors has saved countless lives; now named in his honor, the initiative boasts millions of volunteer donors and has served as a model around the globe.”

-AmericanSpeaks-

Where would you go to get information about clinical trials? (multiple responses allowed)

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>My doctor</td>
<td>60%</td>
</tr>
<tr>
<td>Online</td>
<td>57%</td>
</tr>
<tr>
<td>Hospitals</td>
<td>27%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>25%</td>
</tr>
<tr>
<td>Patient organizations</td>
<td>18%</td>
</tr>
<tr>
<td>Government institutions</td>
<td>16%</td>
</tr>
<tr>
<td>Foundations/charities</td>
<td>16%</td>
</tr>
<tr>
<td>Friends of family</td>
<td>14%</td>
</tr>
<tr>
<td>Other</td>
<td>&gt;1%</td>
</tr>
<tr>
<td>Not sure</td>
<td>15%</td>
</tr>
</tbody>
</table>

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in May 2013.
FDA to Host Workshop on Pediatric Rare Disease Devices
The Food and Drug Administration has announced it will hold a workshop on expediting R&D for pediatric rare disease devices. The event will be held January 6-7, 2014, at FDA headquarters in Silver Spring, MD.

FDA is inviting input from academicians, clinical practitioners, patients and advocacy groups, industry, and other governmental agencies on issues related to medical devices for pediatric patients affected by rare diseases.

Learn more at http://1.usa.gov/17fSSGJ.

Public Health Thank You Day to be Held November 25
Research!America and our public health partners will celebrate Public Health Thank You Day on November 25, the Monday before Thanksgiving.

Public Health Thank You Day is a chance to recognize public health professionals who work tirelessly every day to protect us. From the ordinary to the extraordinary, these heroes keep our drinking water safe, air clean, food supply safe, children healthy and so much more.


Report: 452 New Medicines Being Developed for Rare Diseases
PhRMA has released a report on the development of new medicines and vaccines for rare diseases. Although a condition is only considered “rare” if it affects fewer than 200,000 people in the U.S., there are approximately 7,000 rare diseases which collectively affect more than 30 million people, or 1 in 10 Americans.

To combat this growing problem, biopharmaceutical research companies have developed 452 new medicines and vaccines, targeting a wide range of illnesses including genetic disorders, neurological conditions, infectious diseases and autoimmune disorders. These 452 treatments are all in human clinical trials or under review by the Food and Drug Administration, meaning that they are close to making a real impact. According to the FDA, one third of all new drug approvals in the past five years were for rare diseases.

The full report can be viewed here at http://onphrma/18c93OT.

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Coming UP


Advocacy and Action

Urge Your Policy Makers, Budget Conference Committee to Replace Sequestration

The Budget Conference Committee holds the fate of sequestration, as well as the funding of medical and health research, in its hands. Urge your representative to ask the committee to replace sequestration with sensible prioritization in its upcoming plan. A common-sense budget must advance lifesaving research and invest for a healthier tomorrow. It’s time to kick the sequester to the curb, not down the road! Visit http://bit.ly/Heit6O to send a message to your elected officials today.

Visit US ON THE WEB
www.researchamerica.org

Connect with Research!America Online
Follow us on Twitter: www.twitter.com/researchamerica
Become a fan on Facebook: www.researchamerica.org/facebook
Watch our YouTube channel: www.youtube.com/researchamerica
Visit our blog: www.researchamerica.org/blog
Join us for an evening in Washington, DC, where distinguished supporters of health and medical research gather to celebrate outstanding stars of research advocacy. Please plan to attend and support this event commemorating Research!America’s 25th Anniversary and the advocates who support our mission.

PREVIOUS AwardeES HAVE INCLUDED:
California Institute for Regenerative Medicine
David Baltimore, PhD*
The Honorable Barbara Mikulski
J. Michael Bishop, MD*
Sanjay Gupta, MD
Diane Rehm
John Mendelsohn, MD
Margaret Foti, PhD, MD (h.c.)
Michael J. Fox
Eric S. Lander, PhD
The Honorable Tom Harkin
Juvenile Diabetes Research Foundation
John F. Crowley, JD
The Honorable Michael Bloomberg
Charlie Rose
Mark L. Rosenberg, MD
David Satcher, MD, PhD
Marlo Thomas
The Honorable Richard Burr
The Honorable Bob Casey
Al Hunt and Judy Woodruff
*Nobel Laureate

SPACE IS LIMITED, SO PLEDGE YOUR SUPPORT TODAY AT
www.researchamerica.org/pledgeform2014

About Research!America

Research!America is the nation’s largest 501(c) (3) public education and advocacy alliance working to make research to improve health a higher national priority. Founded in 1989, Research!America is supported by member institutions, organizations and businesses that together represent the voices of more than 100 million Americans. Our public opinion polls, advocacy programs and publications reach the public and decision makers to help advance medical, health and scientific research.
Research!America’s 18th Annual Awards Dinner honors outstanding advocates for medical, health and scientific research whose leadership efforts have been notably effective in advancing our nation’s commitment to research.

The dinner is a high-level gathering of research leaders, attended by the nation’s most influential and esteemed individuals in science, health and medical research, advocacy, business, the media and government. Invited guests include elected and appointed federal officials and top leadership of the National Institutes of Health, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, National Science Foundation and the Food and Drug Administration.

Glenn Close and her family will be honored with the Isadore Rosenfeld Award for Impact on Public Opinion. Urged by her sister and nephew living with mental illness, Glenn Close, the award-winning actress of Damages and Fatal Attraction, co-founded Bring Change 2 Mind, a not-for-profit organization dedicated to ending the stigmas and misunderstandings surrounding mental illness, in 2009.

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Reed V. Tuckson, MD, will be recognized with the Raymond and Beverly Sackler Award for Sustained National Leadership for his work in empowering individuals to take charge of their health as well as his community-based efforts to minimize health care disparities among minorities. His book, The Doctor in the Mirror, focuses on patient empowerment to overcome everyday health issues.

Kathy Giusti, founder and CEO of the Multiple Myeloma Research Foundation (MMRF), will be honored with the Gordon and Llura Gund Leadership Award for advancing the research and treatment of myeloma.

The Progeria Research Foundation (PRF), will receive the Paul G. Rogers Distinguished Organization Advocacy Award for its role for bringing progeria, a rare and fatal pediatric premature aging disease, from obscurity into the forefront of successful translational research and giving hope to both patients and their families.

WEDNESDAY, MARCH 12, 2014
Andrew W. Mellon Auditorium • 1301 Constitution Avenue, NW • Washington, DC
6:15 p.m. - 7:00 p.m. Grand Reception  •  7:15 p.m. - 9:30 p.m. Dinner and Awards

Be a part of this important moment of research advocacy and pledge your support for Research!America’s Annual Advocacy Awards Dinner.

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DOWNLOAD THE PLEDGE FORM AT
www.researchamerica.org/pledgeform2014

Or contact Carol Kennedy at c.kennedy@researchamerica.org or 571.482.2714 to pledge.