2013 Advocacy Award Recipients Announced

The California Institute for Regenerative Medicine (CIRM); biotech entrepreneur John Crowley; cancer researcher John Mendelsohn, MD; broadcaster and author Diane Rehm; and global health researcher Mark Rosenberg, MD, have been named the recipients of the 2013 Advocacy Awards.

The Advocacy Awards will take place Wednesday, March 13, 2013, at the Andrew W. Mellon Auditorium in Washington, DC. The winner of the Edwin C. Whitehead Award for Medical Research Advocacy will be announced in the coming months. CIRM will be presented with the Paul G. Rogers Distinguished Organization Advocacy Award. CIRM was established after California voters approved the California Stem Cell Research and Cures Initiative, which set aside $3 billion for stem cell research at institutions throughout the state. Jonathan Thomas, PhD, JD, chairman of CIRM’s Independent Citizens’ Oversight Committee, will accept the award on behalf of the organization.

Crowley will be presented with the Gordon and Llura Gund Leadership Award. He is currently chairman and CEO of Amicus Therapeutics, a biotechnology company that focuses on

The National Institutes of Health alone would lose $2.53 billion. The Centers for Disease Control and Prevention would lose $470 million, the Food and Drug Administration $318 million, and the National Science Foundation $577 million. The FDA cut includes the diversion of industry-provided user fees, a dangerous precedent that contravenes the goal of speeding new medicines and medical devices to patients and jeopardizes the user fee program as a whole.

Avoiding these cuts would require Congress to reach an agreement that

Majority: Across-the-Board Budget Cuts Aren’t the Way to Go

Which of the following statements comes closer to your view?

 SOURCE: A RESEARCH|AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS, WITH SUPPORT FROM UNITED FOR MEDICAL RESEARCH, IN SEPTEMBER 2012. (TOTALS DO NOT ADD TO 100% DUE TO ROUNDDING.)
Rice University

Rice University has multiple centers that focus on biomedical research of one kind or another. Another center, the James A. Baker III Institute for Public Policy, studies the area that its name implies; one of those areas is the intersection of public policy and science and technology. The program aims to increase scientific engagement with the public and researches the role of medicine and stem cell research in public policy.

Neal Lane, PhD
Kirstin R. W. Matthews, PhD

After a stint in Washington as director of the National Science Foundation and the White House Office of Science and Technology Policy, Neal Lane, PhD, returned to Rice as a faculty member in the Baker Institute in 2001. The institute already had strengths in energy and foreign affairs but was looking for expertise in science and technology policy. As the program grew, Lane gained a trusted deputy in 2003: Kirstin R. W. Matthews, PhD.

Today, the two co-direct the science and technology program of the Baker Institute.

“Our mission that we decided on, when we put this program together, was really to kind of put together scientists with policy scholars and policy makers,” Matthews said. “The whole overall goal is while not everything gets to be decided on science, but at least they have the science—the right science—in front them when making any decisions.”

That mission manifests itself not only in policy research but in programs within the science and technology program: The Civic Scientist Program brings well-known lecturers to campus, highlights contributions of scientists and engineers who have impacted public policy, and brings scientists to local schoolchildren to talk about careers in science. There’s also an initiative with the M.D. Anderson Cancer Center that examines medicine and public policy issues, and the institute’s work on stem cell research policy has helped inform policy makers and the public in Texas and across the country.

“When Kirstin came aboard, she brought an in-depth understanding of [stem cell] science and the potential therapeutic potential, and [she] also knew a lot about the policy implications,” Lane said. “There was a lot going on in Texas in those early years after Kirstin came here. And we worked with people in Texas and nationally on pending legislation.”

To learn more, visit www.bakerinstitute.org/programs/scitech.

Research!America Adds Value

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

- Research!America has conducted public opinion polling since 1992. Our polling asks Americans for their thoughts on research, public health, global health and other topics concerning research to improve health.
- Publications by Research!America explain the importance of health and medical research to Americans. Our previously released report on sequestration has been oft-quoted in trade and mainstream media.
- 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.
New Poll Results Unveiled at Joint Press Conference
Research!America’s new national public opinion poll was released at “The Unkindest Cut of All: Sequestration’s Impact on NIH, from Patients to Research to Jobs,” a joint press conference with United for Medical Research. Speakers provided perspectives on the impact of deep cuts to the research ecosystem. The poll gained significant traction in media outlets such as The Chronicle of Higher Education, National Journal, WAMU-FM and The Washington Post’s Workbook.

Organ Donors Save Lives
In a letter to the editor published in The New York Times, Research!America Board member Herbert Pardes, MD, said participating in organ donation is vital despite hospitals discarding incompatible kidneys. “Today, only a third of people sign donor cards,” Pardes wrote. “If everyone did, or donation were the norm, the number of available healthy kidneys would leap, the waiting list would plummet and lives would be saved.”

OMB Sequestration Reveals Potential Impact
Research!America President and CEO Mary Woolley’s statement reacting to the release of a new White House Office of Management and Budget report on sequestration was included in a CQ HealthBeat news article. “The dollars drained from the research pipeline would knock the wind out of U.S. innovation at the very moment that it is most needed to refuel the economy,” she said.

Democratic and Republic Platforms
As part of the uptick in election news coverage, Eleanor “Ellie” Dehoney was featured in a FDA Week article about positions on medical research in each party platform. “While both parties say they support investments in basic research, neither has come up with a spending plan that includes growth in discretionary spending that will allow advancement in this area,” she said. The article featured statistics from Research!America’s recent sequestration report.

Op-Ed Asks for Candidates’ Stances on Medical Research
In an op-ed published in The Hill’s Congress Blog, Mary Woolley makes a case that likely voters are deeply concerned about scientific progress in the U.S. She urges elected officials to be clear about their views on medical and health research investments. “Furthermore, nearly two-thirds say the next president should announce initiatives promoting medical progress in his first 100 days in office. Yet many candidates have been relatively silent on this issue, failing to address it in speeches, materials and the torrent of campaign advertisements,” she said.

Budget Cuts Will Harm Research, Op-Eds Warn
Op-eds from two Research!America member organizations have appeared in recent days: Gary Gilkeson, MD, and Joan Merrill, MD, of the Lupus Foundation of America, wrote “Sequestration cuts could seriously impair medical research” in The Hill’s Congress Blog. Donna Arnett, PhD, president of the American Heart Association and a faculty member at the University of Alabama at Birmingham School of Public Health, wrote “Research cuts would be unhealthy” for the Montgomery (AL) Advertiser.

Soon the Nobel Prizes will be announced—will candidates for office be talking about their pride in the American (we trust and hope some awardees will be Americans) recipients? If the recent past is any indication, the answer is no. These most prestigious international awards are not much noted by our elected representatives. What a disturbing indication of the lack of priority they place on assuring our nation’s global leadership in years ahead!

Every member of the research stakeholder community should take the opportunity of the announcement of the Nobels to call attention to the awards and the importance of maintaining strong support of science in this country. If enough of us do so, it would go a long way toward overcoming the stunning reality that candidates and Capitol Hill staffers report to us: They are not hearing from all that many members of the research stakeholder community about the importance of prioritizing science. In terms of other high-value issues, they are most definitely hearing from the grassroots—especially about the importance of defense: protecting it from cuts imposed by sequestration or otherwise. If we expect research for health to be protected, we have to show our support—and we have to do it now!

Research!America will help you have an impact. Use our poll and economic impact data to make the case and stay connected with us. Keep informed via my weekly letters; get involved via one or more of our initiatives, including our voter education initiative at www.yourcandidatesyourhealth.org. And register to vote if you haven’t already!
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**Policy Update**

**OMB Releases Report**

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Would either replace or delay the sequester. At the time of this writing, Congress has recessed until after the elections and will return to Washington on November 13. The sequester—along with the expiration of the payroll tax cut, the Bush-era tax cuts and other statutory mandates collectively known as “the fiscal cliff”—may be resolved during the lame-duck session, but this is far from certain. Efforts to address or delay major budget cuts and tax increases are under way, but the outcome of these efforts is, at this point, impossible to call.

Meanwhile, Congress has passed and the president signed a continuing resolution that would essentially flat-fund the government through March. It is important to point out that this legislation does not impact or affect sequestration but is part of the annual appropriations process.

While Congress is in campaign mode, now is an ideal time for constituents to reach out to current Members and their opponents and assert the importance of our nation’s research agencies. Sequestration and the fiscal cliff place research at significant risk, and if Americans who care about medical progress don’t take the time to speak up now, that risk will become a reality. Please don’t hesitate to contact Max Bronstein, director of science policy, at mbronstein@researchamerica.org if you’d like help in your advocacy efforts.

**CPH Foundation Update**

In partnership with the office of Sen. Tom Harkin (D-IA) and the Congressional Study Group on Public Health, the CPH Foundation organized a congressional briefing on public health research data and the National Health and Nutrition Examination Survey (NHANES) data collection program. NHANES is run by the Centers for Disease Control and Prevention’s National Center for Health Statistics and is the gold standard with respect to tracking a range of health measures in the U.S. population. Rep. Bill Cassidy, MD (R-LA), attended the briefing and introduced Tom Frieden, MD, MPH, director of the CDC. Cassidy was also joined on the dais by Ed Sondik, PhD, director of NCHS, and Matt Longjohn, MD, MPH, senior director of chronic disease prevention programs at the YMCA of the USA. If you missed the excellent presentation or the Q&A period that followed, the entire event was recorded and is posted on YouTube at the Foundation’s channel at www.youtube.com/user/TheCPHFoundation.

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**2013 Federal Research Budget**

<table>
<thead>
<tr>
<th>Agency</th>
<th>FY13 President’s Request</th>
<th>FY13 House</th>
<th>FY13 Senate</th>
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<tr>
<td>National Institutes of Health</td>
<td>$30.7 billion</td>
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<td>$30.72 billion</td>
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<td>Centers for Disease Control and Prevention*</td>
<td>$5.07 billion</td>
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<td>Food and Drug Administration</td>
<td>$2.52 billion</td>
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<td>National Science Foundation</td>
<td>$7.4 billion</td>
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<td>$7.27 billion</td>
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<tr>
<td>Agency for Healthcare Research and Quality**</td>
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<td>$0.36 billion</td>
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* CDC core budget. The House bill terminated funding for the Prevention and Public Health Fund.
** Excludes funding from transfers.

Note: At the time of this writing, funding levels have not gone to a floor vote for NIH, CDC, FDA and AHRQ. NSF funding levels have been approved by the House but have not been voted on by the Senate.
The U.S. should not scale back medical research. Cuts are the right way to ease the federal deficit. Moreover, a plurality—49%—thinks Research!America called attention to the looming across-the-board cuts—sequestration—that threaten to derail medical research and American competitiveness.

Rep. Ed Markey (D-MA) and Rep. Brian Bilbray (R-CA) were among the speakers at the event. They were joined by Anastasia Albanese-O’Neill, a volunteer with the American Diabetes Association; Vince Forlenza, chief executive officer of BD; Carrie Wolinetz, PhD, president of UMR; Research!America President and CEO Mary Woolley; and pollster John Zogby.

The poll found that a majority of likely voters do not believe that across-the-board cuts are the right way to ease the federal deficit. Moreover, a plurality—49%—thinks the U.S. should not scale back medical research.

The full results of the poll can be found at www.researchamerica.org/sequestrationpoll.

Garfield Award Winners to be Honored November 15

The winners of the 2012 Garfield Economic Impact Award—Amalia Miller, PhD, of the University of Virginia and RAND Corporation, and Catherine Tucker, PhD, of the Massachusetts Institute of Technology—will be honored with a ceremony in Washington, DC, on November 15. The event will be held at the American Association for the Advancement of Science.

Miller and Tucker authored “Can health care information technology save babies?” The article appeared in the Journal of Political Economy and found that the use of electronic medical records (EMRs) can dramatically lower infant mortality rates. Further, they found the cost of EMRs is minimal when compared with the societal benefits.

The event is sponsored by Merck & Co., Inc., and Research!America. Founding support for the Garfield Economic Impact Award was provided by the Eugene Garfield Foundation. To learn more, visit www.researchamerica.org/economicimpact_award.

Advocacy Awards
Continued from page 1

developing drugs to treat human genetic diseases. The diagnosis of his two youngest children, Megan and Patrick, with Pompe disease inspired Crowley to join the biotech sector. He previously held positions with Bristol-Myers Squibb, Novazyme Pharmaceuticals, Genzyme Therapeutics and Orexigen Therapeutics.

Mendelsohn will be presented with the Geoffrey Beene Builders of Science Award. During his tenure as president of The University of Texas MD Anderson Cancer Center from 1996 to 2011, he oversaw dramatic increases in both size and stature of the institute. Earlier this year, MD Anderson was named the country’s top hospital for cancer care by U.S. News & World Report, the sixth straight year it has been so honored. He currently serves as the director of the Khalifa Institute for Personalized Cancer Therapy at MD Anderson.

Rehm will be presented with the Isadore Rosenfeld Award for Impact on Public Opinion. She is the host of “The Diane Rehm Show,” which is heard on National Public Radio stations throughout the country. Rehm is an honorary director of the National Spasmodic Dysphonia Association; she was diagnosed with spasmodic dysphonia in 1998, and the diagnosis nearly ended her radio career. For the past several years, she—along with her husband, John—has served as co-chair of the Parkinson’s Action Network’s Morris K. Udall Awards Dinner.

Rosenberg will be presented with the Raymond and Beverly Sackler Award for Sustained National Leadership. He is currently president and CEO of The Task Force for Global Health, which performs programmatic work in health system strengthening, immunization and vaccines, and neglected tropical diseases. Prior to joining The Task Force for Global Health, Rosenberg worked for 20 years at the Centers for Disease Control and Prevention. He became the first permanent director of the National Center for Injury Prevention and Control in 1994 and served in that capacity until 1999.

For more information on the 2013 Advocacy Awards dinner, see this month’s insert.
The Association of State and Territorial Health Officials honored Georges Benjamin, MD with the National Excellence in Public Health Award. Benjamin, a Research!America Board member, is executive director of the American Public Health Association.

Christopher P. Austin, MD, was named director of the National Center for Advancing Translational Sciences.

The National Football League donated $30 million in funding for medical research to the Foundation for the National Institutes of Health for brain injuries research.

2012 Lasker Award Winners Announced
The Albert and Mary Lasker Foundation honored the winners of its 2012 Awards. The Albert Lasker Basic Medical Research Award was awarded to Michael Sheetz, PhD, of Columbia University; James Spudich, PhD, of Stanford University; and Ronald Vale, PhD, of University of California, San Francisco. The Lasker-DeBakey Clinical Medical Research Award was awarded to Sir Roy Calne of University of Cambridge (emeritus) and Thomas E. Starzl, MD, PhD, of the University of Pittsburgh. And the Lasker-Koshland Special Achievement Award was awarded to Donald D. Brown, DSc, of Carnegie Institution and Tom Maniatis, PhD, of Columbia University.

“The intellectual rigor and perseverance exhibited by this year’s laureates greatly extended the medical research community’s knowledge of cell biology, led to new surgical techniques that prevented many deaths, and provided a deeper understanding of genetics across generations of scientists worldwide,” Maria Freire, PhD, president of the Lasker Foundation, said in a statement.

The recipients were honored at a ceremony September 21 in New York.

Obama Welcomes PECASE Winners to White House
Ninety-six early-career scientists visited the White House on July 31 to hear encouragement from President Barack Obama and participate in briefings with the Office of Science and Technology Policy. Each of the scientists receives government funding, and the funding agencies nominate each of them. Scientists who receive funding from the Department of Health and Human Services and the National Science Foundation comprised nearly half the group.

“Discoveries in science and technology not only strengthen our economy, they inspire us as a people,” Obama said, according to a White House blog post. “The impressive accomplishments of today’s awardees so early in their careers promise even greater advances in the years ahead.”

Winners Announced for Inaugural Golden Goose Awards
The first winners of the Golden Goose Awards—conceived by Rep. Jim Cooper (D-TN) as a way to inform Members of Congress as well as the public about the value of federal funding for basic science research—have been announced.

The inaugural winners include Nobel laureate Charles Townes, PhD, for his work on the Maser (microwave amplification by stimulated emission of radiation); Osamu Shimomura, PhD; Martin Chalfie, PhD; and Roger Tsien, PhD, for their work generating medical advances from jellyfish; and Della Roy, Eugene White, Rodney White and the late Jon Weber for their work on making bone grafts from coral.

To be eligible for the awards, researchers must have received a federally funded grant for research within the past 60 years which led to an important breakthrough.

To learn more about the winners or the awards, visit the initiative’s website at www.goldengooseaward.org.

49% of Americans Say U.S. Should Not Scale Back Medical Research

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<th>Option</th>
<th>Percentage</th>
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<tr>
<td>Our nation should not scale back medical research.</td>
<td>49%</td>
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<tr>
<td>It is OK to scale back medical research as part of deficit reduction.</td>
<td>34%</td>
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<tr>
<td>Not sure</td>
<td>17%</td>
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SOURCE: A RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS, WITH SUPPORT FROM UNITED FOR MEDICAL RESEARCH, IN SEPTEMBER 2012.
Science, Technology and Policy Forum Holds First Meeting

Senators, Nobel laureates and other research stakeholders came together in mid-September for the first meeting of the Science, Technology and Policy Forum. The first meeting of the forum, organized by the National Academies, focused on the human genome and its implications for medicine.

Future forums are expected to encompass other topics in science, technology and medicine.

Research!America Board member Carol Greider, PhD, was one of five Nobel laureates at the meeting. The others included Bruce Beutler, MD; Michael Bishop, MD (a 2011 Research!America Advocacy Award recipient); Thomas Cech, PhD; and Phillip Sharp, PhD. Among the senators at the meeting were Sen. Jay Rockefeller (D-WV), chairman of the Senate Commerce, Science and Transportation Committee, and Sen. Kay Bailey Hutchison (R-TX), the ranking member on the committee.

Special Thanks To New and Renewing Research!America Alliance Members

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<td>Bonnie J. Addario Lung Cancer Foundation</td>
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<td>Mylan Specialty L.P.</td>
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<tr>
<td>Baylor College of Medicine</td>
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<td>Clinical Research Forum</td>
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<td>Conference of Boston Teaching Hospitals</td>
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<td>FasterCures, The Center for Accelerating Medical Solutions</td>
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<td>Friedreich’s Ataxia Research Alliance</td>
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<td>David Geffen School of Medicine at UCLA</td>
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| The George Washington University           |
| Juvenile Diabetes Research Foundation     |
| International Kidney Cancer Association   |
| Massachusetts Institute of Technology     |
| Mayo Clinic                               |
| The New York Academy of Medicine          |
| Ohio University College of Osteopathic Medicine |
| Ostrow School of Dentistry of USC         |
| Rice University                           |
| Tufts University                          |
| University of Chicago, Pritzker School of Medicine |

Not yet a member? Join Research!America today at www.researchamerica.org/supportourwork

Yes, medical research takes place in every state in the U.S. 44%
No, medical research does not take place in every state in the U.S. 21%
Don’t know 35%

Sens. Chris Coons (D-DE) and Roger Wicker (R-MS) announced that the Senate Malaria Working Group was expanding to an official Senate congressional caucus focused on combating 17 neglected tropical diseases, or NTDs, in addition to malaria. With NTDs affecting more than 1.4 billion people worldwide and increasing reports of NTDs here in the U.S., this commitment to finding new solutions is good news. Past U.S. government involvement in the fight against NTDs has yielded promising results.

The National Institutes of Health has funded crucial basic research for NTDs, and the U.S. Agency for International Development’s NTD program has made remarkable progress toward controlling several NTDs with existing treatments. Despite this progress, some of the most commonly used treatments are not effective or have toxic side effects, and a majority of these diseases lack vaccines or appropriate diagnostics. Increased funding and research to address these gaps includes the Centers for Disease Control and Prevention surveillance efforts as well as new prevention and treatment methods. These tools are vital for the global effort to combat NTDs.

America Speaks

To the best of your knowledge, would you say that medical research takes place in every state in the U.S.?

Yes, medical research takes place in every state in the U.S. 44%
No, medical research does not take place in every state in the U.S. 21%
Don’t know 35%

Source: A Research!America poll of likely voters conducted in partnership with JZ Analytics, with support from United for Medical Research, in September 2012.
As the election draws near, it is critical for you to reach out to candidates and ask them to participate in the *Your Candidates—Your Health* initiative, in which candidates complete a short questionnaire on medical research issues.

As you well know, funding for research is declining despite the incredible promise for new cures and treatments enabled by genome sequencing and other recent breakthroughs. Looking ahead, federally funded medical research is at greater risk than ever as across-the-board cuts to cancer, Alzheimer’s, diabetes and other critical research looms. That is why it is so important for you to know whether candidates care about research or perceive it as a low priority.
Advocacy Awards

WEDNESDAY, MARCH 13, 2013

Join us for an evening in Washington, DC, where distinguished supporters of health and medical research gather to celebrate outstanding advocacy. Show your support and honor our stars of research advocacy.

PREVIOUS Awardees HAVE Included:

Susan Axelrod, Citizens United for Research in Epilepsy
David Baltimore, PhD*
The Honorable Barbara Mikulski
Michael Bishop, MD*
Sanjay Gupta, MD
Katie Couric
Michael J. Fox
The Honorable Tom Harkin
The Honorable Orrin G. Hatch
Al Hunt and Judy Woodruff
Juvenile Diabetes Research Foundation
C. Everett Koop, MD, ScD
Eric S. Lander, PhD
The Honorable Nancy Pelosi
Former First Lady Nancy Reagan
Charlie Rose
David Satcher, MD, PhD
Marlo Thomas
Bob Woodruff
The Honorable Michael Bloomberg
The Honorable Richard Durbin

* Nobel Laureate

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.

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1101 King Street, Suite 520 | Alexandria, VA 22314-2960 | P: 703.739.2577 | F: 703.739.2372 | 1.800.366.CURE (toll free)
Research!America’s 17th 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.

John F. Crowley JD, MBA, CEO and chairman of Amicus Therapeutics, Inc., will be recognized with the Gordon and Llura Gund Leadership Award for his patient advocacy efforts to accelerate new treatments for Pompe disease and other genetic diseases.

John Mendelsohn, MD, director of the Kahalifa Institute for Personalized Cancer Therapy at The University of Texas M.D. Anderson Cancer Center, will be awarded the Geoffrey Beene Builders of Science Award for pioneering translational research that has transformed cancer treatment and provided the foundation for targeted cancer therapies that are benefiting thousands of cancer patients worldwide.

Mark L. Rosenberg, MD, executive director of The Task Force for Global Health, will be honored with the Raymond and Beverly Sackler Award for Sustained National Leadership for his dedication to advancing the injury prevention and road safety field, and redefining these areas as public health priorities.

Diane Rehm, host of The Diane Rehm Show on National Public Radio, will receive the Isadore Rosenfeld Award for Impact on Public Opinion for raising awareness about the importance of medical research to combat life-threatening illnesses and educating the public about the benefits of research through her nationally-syndicated radio show.

California Institute for Regenerative Medicine will receive the Paul G. Rogers Distinguished Organization Award for its advocacy to improve stem cell research, and on the potential development of a new generation of promising therapies for untreatable human disorders.

2013 HONOREES:

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