Funding for science in FY14 simply does not reflect the value it delivers to America and Americans. As Congress negotiates federal funding levels for FY15, we must convince policy makers that funding for medical progress must be assigned a far higher priority. Learn more on page 8.

At Research!America’s Annual Meeting of Members on March 12, four leaders in the research community were elected to serve their first term on the organization’s Board of Directors. Research!America’s members also voted for seven other Board members to serve an additional three-year term.

The new Board members are Hortensia Amaro, PhD, of the University of Southern California; Larry Hausner, MBA, of the American Diabetes Association; E. Albert Reece, MD, PhD, MBA, of the University of Maryland; and Gregory Sorensen, MD, of Siemens Healthcare North America.

Amaro is associate vice provost for community research initiatives and Dean’s Professor of Social Work and Preventive Medicine at the University of Southern California. Before joining USC in 2012, Amaro was with Northeastern University for 10 years, serving as associate dean and distinguished professor of health sciences and counseling psychology of the Bouvé College of Health Sciences as well as director of the

Scientists are Trusted Spokespersons for Science

How trustworthy do you consider them to be?

81% trustworthy

10% not trustworthy

9% not sure


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National Institutes of Health Dedicates John Edward Porter Neuroscience Research Center

The newest building on the campus of the National Institutes of Health has been dedicated to the work of Research!America’s chair, former Congressman John Edward Porter. The John Edward Porter Neuroscience Research Center, officially dedicated March 31, honors Porter’s decades of advocacy for medical research.

“The legacy of his leadership can be seen today in this very building, in the new hope for patients across the country and around the world,” said NIH Director Francis Collins, MD, PhD.

Several current and former elected officials attended the ceremony. Among them were three sitting Members of Congress, Sen. Tom Harkin (D-IA), Rep. Chaka Fattah (D-PA) and Rep. Andy Harris, MD (R-MD); former Cabinet members Norman Mineta and Louis Sullivan, MD; former Sen. John Warner; and former Reps. Norm Dicks, Bob Michel, Connie Morella and Louis Stokes (also a Research!America emeritus director).

“In times of great change, there are two kinds of leaders. There are those who usher out the old, and they’re called the pallbearers; and those who usher in the new, and they’re called the torchbearers,” Harkin said.
On the occasion of the dedication of the largest research building on the campus of the National Institutes of Health (NIH) on March 31, named in his honor by act of Congress, former Congressman John Edward Porter quoted Louis Pasteur, who famously remarked, “Chance favors only the prepared mind.” Mr. Porter selected a more extended and a more nuanced translation of this popular quotation, drawing on it to underscore important events in his career that offered him the opportunity to serve the public’s interest. His typically humble but forceful remarks played down his own (considerable) accomplishments as he saluted those of others. He also issued a call to action. He has been issuing those calls, to the science community and all those who are stakeholders in science, regularly. Here are a few of his maxims, every one of them worth your consideration—and then your action as an advocate!

- “You can change the image of things to come. But you can’t do it sitting on your hands … The science community should reach out to Congress and build bridges.”
- “Wouldn’t it be wonderful if all candidates had science advisers or science advisory committees? They will, if individual scientists step up to the plate.”
- “Your country needs you. If all you do is vote, you’re definitely not doing enough. Get off your chair, do something outside your comfort zone and make a difference for science.”
- “America’s economic destiny lies in innovation, technology, science and research.”

On behalf of the Board, staff and membership of the Research!America alliance, I offer deep gratitude and appreciation to John Porter, and congratulate him on this high honor.
Appropriations Process Moves Along

With a top-line budget approved last year, the appropriations process through which Congress allocates funds to government agencies is moving forward. The House and Senate appropriations committees are currently holding hearings for the dozen appropriations subcommittees, a process which started in March and will extend through the summer. At these hearings, testimonies for the dozen appropriations subcommittees, a process which started in

The House and Senate appropriations committees are currently holding hearings for the appropriations process. Our advocacy alerts have reached Members of the House and Senate and asked them to include health research agencies among the appropriations priorities they submit to their respective appropriations committees. Research!America has also submitted testimony requesting robust funding for these agencies, and we have promoted House and Senate sign-on letters that support robust funding for NIH and NSF.

The annual appropriations process is critical to the continued success of research conducted across the country. Assistant Senate Majority Leader Richard Durbin (D-IL) and other policy makers have proposed measures that would supplement appropriated funding. Under Durbin’s bill, a mandatory trust fund to build on annual appropriations would be created for NIH and other key agencies. To ensure this fund would supplement, not supplant, appropriated dollars, the fund would only be triggered if annual appropriations meet specified levels. Congress has also shown its commitment to advancing medical research by sending the bipartisan Gabriella Miller Kids First Research Act to President Barack Obama. The message coming from both House and Senate is bipartisan and it is clear: It is smart, and right, to treat medical research as a top national priority.

America Speaks, Vol. 14, Released

Research!America’s annual compendium of poll data, America Speaks, has been released. This year’s edition, Volume 14, highlights a year’s worth of polling commissioned by Research!America and was made possible through a contribution from the American Medical Association.

Included in the publication is polling, conducted in January, that has not been previously released. Among those findings, two-thirds of Americans (66%) say it’s important for candidates running for office to assign a high priority to funding medical research. And while Americans place a high value on U.S. leadership in medical innovation, only 12% say they are very well informed about the positions of their senators and representatives when it comes to their support of medical and scientific research.

Additionally, 74% of respondents say it’s important to know whether their candidates for Congress are supportive of medical and scientific research. And 80% do not believe elected officials in Washington are paying enough attention to combating the many deadly diseases that afflict Americans.

Four New Directors Elected continued from page 1

Jennifer Doudna Wins 2014 Lurie Prize

Structural biologist Jennifer Doudna, PhD, of the University of California, Berkeley, has been named the second winner of the Lurie Prize in the Biomedical Sciences by the Foundation for the National Institutes of Health.

Doudna is noted for her discovery of clustered regularly interspaced short palindromic repeats, or CRISPR, a gene-editing technique. Science recognized CRISPR as one of its runners-up for breakthrough of the year in an article in December.

“CRISPR is, indeed, an exciting area of science, and it will be most fascinating to watch as additional research moves it closer to clinical applications,” said FNIH Chairman Charles A. Sanders, MD. “Jennifer Doudna has not only contributed a groundbreaking technology, she has advanced her entire field.”

Philanthropist Ann Lurie has endowed the Lurie Prize, which recognizes a promising scientist who is age 52 or younger. Ruslan M. Medzhitov, PhD, of Yale University, won the inaugural Lurie Prize in 2013.

CPH Foundation Update

The CPH Foundation is working with committee staff in the Senate and with the Centers for Disease Control and Prevention to plan a late-May tour of the agency for Senate staff members working with the HELP Committee. Nonprofit organizations wishing to assist the Foundation in executing this important two-day educational effort should contact Executive Director Karl Moeller at karlm@CPHFoundation.org.

Also, through a new memorandum of understanding between CPHF and the American Public Health Association, APHA generously donated workstations in its downtown Washington, DC, office for use by the Foundation. This prime space will help CPHF attract graduate-level interns from surrounding universities. Interested graduate students can learn more about CPHF internships at http://bit.ly/1l111AI.

2014 Federal Research Budget*

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<th>FY13 POST-SEQUESTRATION</th>
<th>FY14 ENACTED</th>
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* reflects budget authority excluding transfers
Advocacy Awards Dinner
Research!America’s 2014 Advocacy Awards Dinner, which honored leaders in medical and health research advocacy, was highlighted in The Hill, The Washington Post, Nature and Genome Web, as well as in numerous online news sources including Philly.com, Boston.com, CBS Marketwatch and Wired.com.

Research!America Commemorates 25th Year
Northern Virginia Magazine interviewed President and CEO Mary Woolley about Research!America’s 25th anniversary, the current landscape for U.S. scientists and the state of the nation’s global leadership in R&D. “Looking further ahead, we will continue to urge, through all different kinds of advocacy efforts, our Congress to address tax and entitlement reform and get the nation out of this kind of quicksand effect of pulling us down,” Woolley said.

Fewer Grants for Young Scientists
An op-ed in The Wall Street Journal penned by Ronald Daniels, JD, LLM, president of Johns Hopkins University, and Paul Rothman, MD, CEO of Johns Hopkins Medicine and dean of Johns Hopkins School of Medicine, called on the need for the U.S. to invest in the careers of scientists. “We must recalibrate our research policies to fuel the promise of the most talented individuals of all ages, with solutions on three fronts: reinvestment, re-examination and reimagination.”

Giusti Recognized as Great Leader
Kathy Giusti, founder and CEO of the Multiple Myeloma Research Foundation (MMRF) and recipient of Research!America’s 2014 Gordon and Llura Gund Leadership Award, was named one of the World’s 50 Greatest Leaders in Fortune magazine.

Data Shows Funding for Investigators in Decline
Science magazine featured a recent analysis by Jeremy Berg, PhD, president of the American Society for Biochemistry and Molecular Biology, that showed the sequester resulted in 1,000 fewer funded investigators. In the analysis, posted originally on the ASBMB blog, Berg writes, “Is this a wise culling of the herd, or is this a destructive loss of productive investigators and talent?”

Research!America In the News
Research!America’s polling about public support for research was included in an op-ed piece on NJ.com written by Kenneth Adler, MD, chair of the New Jersey Commission on Cancer Research, about the threat of state budget cuts to cancer research.

In a piece written for The Huffington Post by Linda Fried, MD, MPH, dean and DeLamar Professor of Public Health at Columbia University Mailman School of Public Health, she referenced Research!America’s investment report to illustrate the decline in R&D spending in the U.S.

IN BRIEF
- Thanks to greater use of colonoscopies, colon cancer rates have dropped 30% in the U.S. in the past decade, according to a report from the American Cancer Society.
- Health care analytics firm ArborMetrix announced that Mark McClellan, MD, PhD, has joined its board of directors. McClellan is a Research!America Board member.
- On March 12, the Senate confirmed France Córdova, PhD, as the new director of the National Science Foundation.
- James E. Stowers, Jr., medical research benefactor and the winner of the 2009 Gordon and Llura Gund Leadership Award, died on March 17 at age 91.
Michael Milken, Sumner Redstone Donate $80M to GWU for Public Health Efforts

Through their foundations, Michael Milken and Sumner Redstone have donated a combined $80 million to George Washington University to support efforts to prevent disease and promote wellness. The donation is the largest in the school’s history.

Portions of the school will bear the names of Milken, a financier, and Redstone, majority owner of CBS, Viacom and other media outlets; both are also prostate cancer survivors.

The donation includes $40 million from the Milken Institute for new and ongoing research and scholarships; $30 million from the Sumner M. Redstone Charitable Foundation for the development of strategies to expand wellness and the prevention of disease; and $10 million from the Milken Family Foundation to support the dean of GWU’s school of public health.

“We need to effect a change in leadership in prevention and wellness, and you need a presence in the area where health policy’s being made,” Milken told The Washington Post.

FasterCures, a center of the Milken Institute, is a Research!America member.

PhRMA, NMQF Launch Campaign to Increase Diversity in Clinical Trials

PhRMA, a Research!America member, and the National Minority Quality Forum have launched the “I’m In” campaign to raise awareness about clinical research and encourage greater participation by diverse patient populations.

 Minority groups are often underrepresented in clinical research. According to data from the Food and Drug Administration, for instance, African-Americans make up 12% of the American population but only 5% of clinical trial participants; Hispanics make up 16% of the population but only 1% of clinical trial participants.

“PhRMA and our member companies are committed to raising awareness and increasing participation in clinical trials, particularly among historically underrepresented populations,” John Castellani, president and CEO of PhRMA, said in a press release. “Through this collaboration of health care leaders, we are taking a major step forward to help reduce health disparities through greater inclusiveness in clinical research.”

“Increased diversity in clinical trials could help researchers find better ways to fight diseases that disproportionately impact certain populations, and may be important for the safe and effective use of new therapies,” said Gary Puckrein, PhD, president and CEO of the National Minority Quality Forum.

To learn more, visit www.joinimin.org.

John Edward Porter Neuroscience Research Center continued from page 1

“Across three and a half decades, John Porter has been one of America’s most ambitious and accomplished torchbearers for biomedical research. And it is fitting that this magnificent neuroscience research building now bears his name.”

“Now is the time to impact Congress and the administration as never before,” he said. “Scientists are the most respected people in America. They will be listened to if they only engage with their Member of Congress and make a difference. Get out of your comfort zone and impact decisions made on the Hill.”

The Porter Neuroscience Research Center will bring together more than 800 scientists in 85 laboratories from 10 of NIH’s 27 institutes and centers in an effort to foster collaboration.

According to NIH, the facility is one of the largest neuroscience buildings in the world.

Visit www.researchamerica.org/25years to read our commemorative book or view our commemorative video!
The Orthopaedic Research Society recently held its 60th annual meeting in New Orleans; the four-day event welcomed more than 3,000 attendees. (The original annual meeting was one day, and eight were in attendance.) ORS is comprised of around 2,900 members; slightly more than 2,000 are based in the U.S. Most are bioengineers, orthopaedic surgeons, biologists and veterinarians.

The musculoskeletal system gives us shape and allows us to move—and is the primary concern of those involved in orthopaedic research. Typically, some associate “bone” to orthopaedics; broken bones, but it is so much more. The musculoskeletal system also includes cartilage, ligaments, tendons, joints and muscle. The areas of research conducted by ORS’ membership is broad, as it includes the entire musculoskeletal system and our moving parts; hips, knees, shoulders, elbows, hands, ankles, feet, wrists and spine. As ORS Executive Director Brenda Frederick points out, all of us know someone who suffers from, or has suffered from, a musculoskeletal disease or injury that may be more commonly known as a torn ACL, or rotator cuff, bad hip or knees, or suffer from back pain or arthritis. In fact, “musculoskeletal disorders, injuries and disease are the leading cause of disability in the United States, with an estimated $950 billion annually in direct health care costs and lost wages,” Frederick said.

But like so many other areas of research, orthopaedic research has been affected by sequestration and other budget cuts. The National Institutes of Health, through the National Institute of Arthritis and Musculoskeletal and Skin Diseases, is the primary funder of research for ORS members, but other funding sources include the Department of Defense, private foundations and grants.

“Across the board, funding for musculoskeletal research has decreased, leaving many unanswered questions in basic, translational and clinical orthopaedic/musculoskeletal research,” Frederick said.

ORS’ advocacy is a key tenet in changing this. Its board of directors has a committee dedicated to advocacy, currently led by Lynne Jones, PhD, of John Hopkins Medicine. ORS, along with other orthopaedic groups, also supports a Capitol Hill day—an annual event for more than two decades—that brings together researchers, practitioners and patients for outreach to elected officials.

Other ORS programs include the New Investigator Workshop, held jointly with the American Academy of Orthopaedic Surgeons and the Orthopaedic Research and Education Foundation in May. The workshop aims to help young researchers secure funding for their work. In the fall, ORS will partner with the Icahn School of Medicine at Mount Sinai for a meeting called New Frontiers in Tendon Research.

Research!America’s work in advocacy complements ORS’ efforts, and that is an important reason for the organization’s membership. “The resources provided by Research!America have proven to be very valuable and will provide us with a basis from which to develop our advocacy agenda,” Frederick said. “The Research!America website also provides valuable resources and information that can be used to improve our advocacy efforts. In addition, the ties to Capitol Hill are invaluable. We have also appreciated their level of professionalism and expertise.”

Learn more at www.ors.org.
Boost Funding for Medical Research in 2015; The Time to Act is Now

In recent years, our research enterprise has been buffeted by deep budget cuts, a strategic mistake that compromises medical progress and the multi-faceted public health, fiscal and economic benefits such progress conveys. The latest budget provided increased funding for NIH, FDA, CDC, NSF and AHRQ, but in the case of NIH in particular, policy makers settled for a funding level that is actually lower than NIH received in FY12. Overall, funding for science in FY14 simply does not reflect the value it delivers to America and Americans. As Congress negotiates federal funding levels for FY15, we must convince policy makers that funding for medical progress must be assigned a far higher priority. Send a message to Congress making the case for robust investment in NIH and the other federal agencies that support research leading to medical progress. Learn more at http://bit.ly/1cuRgt1.

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2014
ADVOCACY
AWARDS
DINNER

RESEARCH AMERICA
AN ALLIANCE FOR DISCOVERIES IN HEALTH
COMMEMORATING 25 YEARS
ISADORE ROSENFELD AWARD FOR IMPACT ON PUBLIC OPINION
Glenn Close, Jessie Close and Calen Pick

“The journey began when Jess came to me and said, ‘I need your help. I can’t stop thinking about killing myself.’ And it was a shock, but it began our journey. And it’s been a magnificent journey, and one that we will not end until people are speaking about mental illness in this country—and hopefully around the world—with the same lack of fear and shame as they do with any other chronic illness.”

EDWIN C. WHITEHEAD AWARD FOR MEDICAL RESEARCH ADVOCACY
Rep. Frank Wolf (R-VA) and Rep. Chaka Fattah (D-PA)

“First, the funding in our committee, for the sciences and the National Science Foundation, is at a record high—real dollars, inflated dollars, but it is at a record high. Second, I am a Reagan Republican. Mr. Fattah is, I think, an Obama Democrat. And we work well together, we like each other, and we have gotten a lot done.”—Rep. Frank Wolf (R-VA)

“We are just at the beginning of our efforts ... Upon the request of the European Union’s Human Brain Project and its leadership, together with their counterparts here in the United States BRAIN Initiative, I’ve been asked and I’ve agreed to develop a memorandum of understanding that will create the most significant scientific collaboration ever on brain research. I can’t think of a more important scientific relationship in history.”—Rep. Chaka Fattah (D-PA)

RAYMOND AND BEVERLY SACKLER AWARD FOR SUSTAINED NATIONAL LEADERSHIP
Reed Tuckson, MD, managing director, Tuckson Health Connections

“Tonight, I commit to Research!America and to all of you that I will redouble my efforts as an advocate for this incredibly talented community of scientists and clinicians. We deserve to give them our best. And above all, our nation deserves the best we can give them.”

OUR HONOREES
**GORDON AND LLURA GUND LEADERSHIP AWARD**

**Kathy Giusti, founder and CEO, Multiple Myeloma Research Foundation**

“Every morning I wake up to emails and phone calls from patients who have relapsed, run out of options, and they are dying. Our disease is still fatal. I know we have to do more, not just in myeloma, but across all cancers. Because 1 in 3 of us will be diagnosed, and 1 in 4 of us will die of this disease.”

**PAUL G. ROGERS DISTINGUISHED ORGANIZATION ADVOCACY AWARD**

**Progeria Research Foundation**

**Leslie Gordon, MD, PhD, Medical Director**

“We thank you for showing us what is possible when industry, government, scientists, physicians and patient advocacy groups work together.

Each of us brings different strengths and together, we make progress where individually we never could.”

**GEOFFREY BEENE BUILDERS OF SCIENCE AWARD**

**Leroy Hood, MD, PhD, president and co-founder, Institute for Systems Biology**

“In taking the systems approach to medicine, it’s obvious to me that health care is really about two things: one is wellness and the second is about demystifying disease. With regards to wellness, what we really need are metrics for being able to assess how well we are. Now, the definitions are vague and psychological.”
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March 11, 2015

www.researchamerica.org/advocacy_awards

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