Research!America Members Elect Two New Board Members

The Honorable Patrick Kennedy, who represented Rhode Island’s 1st Congressional District for 16 years, and Keith Yamamoto, PhD, vice chancellor for research at the University of California, San Francisco, have been elected to the Research!America Board of Directors. Both were elected during Research!America’s Annual Meeting of Members, held March 14 in Washington, DC.

Kennedy is predominantly known as the author and lead sponsor of the Mental Health Parity and Addiction Equity Act of 2008. This dramatic piece of legislation provides tens of millions of Americans who were previously denied care with access to mental health treatment. Since leaving Congress, Kennedy has continued to pursue the cause of advancing brain research through the creation of the One Mind for Brain Research campaign, a nationwide coalition of advocates, researchers and clinicians that he co-chairs.

Yamamoto is professor of cellular and molecular pharmacology, executive vice dean of the School of Medicine, and vice chancellor for research at UCSF.

New Poll Data Shows Americans Increasingly Pessimistic about U.S. Leadership

A survey of likely U.S. voters shows that fewer than half believe America will be a world leader in health care or in science and technology by 2020—just eight years from now. The new polling data, compiled in Research!America’s partnership with JZ Analytics, was released at Research!America’s events on March 14.

When asked about their feelings on U.S. rankings today, respondents’ attitudes were similarly skeptical: Only 23% consider the U.S. to be the world leader in health and medical research today. That contrasts sharply with Americans’ aspirational attitudes; 91% said it’s important for the U.S. to maintain its role as a world leader. Fifty-seven percent have a negative reaction upon hearing that federal spending on medical and health research has declined in the past 5 years when adjusted for inflation. And 54% said health and medical research should be exempt from across-the-board spending cuts as outlined in the Budget Control Act of 2011.

Other poll highlights include:
- 65% of Americans say it’s important that the U.S. is a leader in medical and health research;
- 85% of likely voters are concerned about the impact of decreased federal investment in research, including the possibility of scientists leaving.

Despite Skepticism, Americans Aspire to World Leadership

![Bar chart showing poll results]

**SOURCE:** A RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS IN MARCH 2012.

... If current trends continue, other nations will soon match U.S. investment in research and development. In your opinion, how important is it for the United States to maintain its world leadership role?
The namesake of the Jackson Gabriel Silver Foundation was born in October 2007 and, shortly afterward, diagnosed with epidermolysis bullosa. Silver’s condition, in which a protein deficiency prevents layers of skin from properly bonding together, led his parents to form a foundation in his honor 2.5 years later. Today the foundation funds research aimed at treating and curing EB, which appears tantalizingly close.

Alex Silver and his wife, Jamie, never expected their son to be born with a rare disease, but before long, they became fully engaged in the EB community. Their involvement started soon after their son’s birth with The Dystrophic Epidermolysis Bullosa Research Association of America, or Debra, which focuses on patient care in addition to research. But the Silvers saw a need for a group to fund and promote EB research solely. From there, JGSF was born.

The organization now helps support leading global EB researchers, as well as the Epidermolysis Bullosa Clinical Research Consortium. Most importantly, the work of JGSF and the other EB organizations seems to be paying off. There are multiple ways of treating and curing EB being investigated, Silver said, including protein replacement therapy and gene and stem cell therapies.

“Four years ago, protein therapy was published in papers,” Silver said. “Today there is venture capital funding that will continue down the path of proving this out.

“This form of therapy is not a cure, but it’s a game changer. … Imagine falling down and not losing the skin on your palms. We are talking about a potentially enormous change in the quality of life.”

For Silver, a membership with Research!America helps him and the organization stay on top of the legislative climate.

“We have been living in a time of great economic strain, of course,” he said, “so how you allocate your resources is more important than ever … To be part of Research!America, which continues to advocate for those affected by rare diseases while we’re spending our time focusing on curing EB, is a huge asset, it really is.”

To learn more, visit www.jgsf.org.

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, 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.
- 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.
- Our National Health Research Forum brings together thought leaders from throughout the research world to examine the current and future landscape of research to improve health. Federal agency leaders, nonprofit executives, researchers and key media lead a discussion that informs Research!America membership and members of the public who care about research.
Media

Coverage of National Health Research Forum, Poll

Advocacy Awards Honors Top Scientists and Advocates
Roll Call, The Hill and Glittarazzi.com captured some of the festivities during Research!America’s Advocacy Awards dinner. Roll Call provided a recap of the evening and shared remarks from Advocacy Award winner Sen. Barbara A. Mikulski (D-MD). San Jose Mercury News/Saratoga News, based in California, also featured an article on Scott Johnson, this year’s winner of the Gordon and Llura Gund Leadership Award.

Research!America Chairman Porter quoted in PMLive
In an article from PMLive, which covers the pharmaceutical industry, former Congressman and Research!America Chair John Edward Porter warns that a freeze on investments in biomedical research could have devastating consequences. “Congress needs to do the hard work of tax and entitlement reform while protecting investments that make absolute sense for our country,” Porter said.

UnitedHealth Group: Spending on Genetic Tests to Rise
A study conducted by UnitedHealth Group shows that spending on genetic tests could rise as much as $20 billion during the next decade. The study was featured in an article in the March 12 issue of the Los Angeles Times and quoted Reed Tuckson, MD, executive vice president and chief of medical affairs and a Research!America emeritus director.

BioCentury, Houston Chronicle Feature Mary Woolley
Mary Woolley, president and CEO of Research!America, was recently a featured guest on the BioCentury television program. During the segment, Woolley expressed her concerns about the U.S.’s ability to stay globally competitive and the impact of insufficient funding for research. Woolley was also quoted in a Houston Chronicle blog, where she emphasized the need for scientists to advocate for their role in society. The Chronicle also featured a Research!America poll result in which it was noted that most Americans can’t name a living scientist.

Advocates Author Op-Eds on Funding Medical Research
Gilbert S. Omenn, MD, PhD, of the University of Michigan, authored the commentary, “U.S. must recommit to funding medical research,” in The Detroit News. Research!America treasurer and board member Mary J. C. Hendrix, PhD, president and scientific director, Children’s Memorial Research Center, authored an op-ed that was featured in The Chicago Tribune. The Honorable Louis W. Sullivan, MD, Research!America emeritus director and former secretary of the Department of Health and Human Services, expressed his concerns in an op-ed that President Barack Obama’s budget recommendation to freeze funding to the National Institutes of Health is shortsighted. The op-ed was featured in nearly a dozen McClatchy newspapers across the country.

President’s MESSAGE
April is upon us and that means the appropriations season—like our spring weather—is heating up! And the season may very possibly extend beyond the November election, with a lame-duck Congress making key decisions. This is just one of many reasons to be engaged in what our chair, John Porter, is calling “the most important election in my lifetime.” So much is at stake: the economic destiny of our nation, as well as delivering better health and quality of life, with the increases in productivity and cost saving that historically accompany research advances.

If you haven’t read our very recent public opinion poll of likely voters, it is well worth your time. Voters have low confidence that the U.S. can retain our world leadership status in science and high expectations that we take steps to prevent this from happening. The voting public is on our side, in concept, but is not likely to become our advocates if stakeholders don’t participate themselves. The election-year field is crowded with issues and advocates; stakeholders in research must speak out in much greater numbers than our community has accomplished thus far. We can’t be content with mile-wide but only inch-deep public support, and we can’t count on others to do our part for us.

The need for stronger, unified advocacy was one of the driving themes of our National Health Research Forum on March 14. The power of the day was such that all of us at Research!America are re-energized in pursuit of our mission. We know that advocates change history. Research advocates have done it before; we can do it again. Now is the time for us all to engage.

Mary Woolley

The RESEARCH ADVOCATE
House, Senate Begin Work on FY13 Budgets

Now that the president’s budget has been released to Congress, the House and Senate are setting overall spending limits. On March 20, Rep. Paul Ryan (R-WI) released his budget plan, which proposes a spending reduction of $19 billion below the spending limits set in last year’s Budget Control Act (BCA). As of this writing, it is unclear how the cuts would be allocated between defense and non-defense discretionary spending, but it is possible that defense spending would be spared or even increased, meaning even deeper cuts to non-defense spending on such priorities as medical research.

The Senate has not yet released an official recommendation for overall government spending, but Senate leadership has indicated that they plan to abide by the levels established in the BCA. This discrepancy could result in a protracted budget debate between the House and Senate.

The lower spending limits proposed in the House could well result in less funding for the House Labor, Health and Human Services, Education and Related Agencies subcommittee, which sets funding levels for the National Institutes of Health, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality, as well as the House Subcommittee on Agriculture, which sets funding levels for the Food and Drug Administration. On top of these budget debates, the sequester is scheduled to take effect in early January 2013, which would require automatic cuts of 7% to 9% to all agencies. Cuts of this magnitude would be disastrous for medical research.

The bottom line is that enhanced advocacy is needed now more than ever. Research for health is a critical national priority that is too important to cut, and we must work together to make sure policy makers, political candidates and voters get the message.

CPH Foundation Update

The CPH Foundation, as it normally does at this time of year, analyzed the Centers for Disease Control and Prevention’s portion of the administration’s FY13 budget request to Congress soon after its release in February. What it found was stunning: a huge, $1.4 billion cut in CDC’s budget authority since 2010. While there was an effort to backfill some of those cuts with dollars from other budget lines, the backfill dollars come from unstable and threatened sources of funds.

The CPH Foundation checked the impact of inflation; the president’s FY13 request, in constant dollars, cuts the CDC back a decade to 2003 funding levels. Nature Magazine picked up on the Foundation’s blog post about these cuts and wrote a detailed story based on the Foundation’s analysis in its March 1 print publication. The Foundation will continue to work to make the gravity of these cuts known and will continue to track funding and has plans for continued analysis as the budget debates continue this year.

### 2012 Federal Research Budget

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<th>Agency</th>
<th>FY12 Enacted</th>
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<td>National Institutes of Health</td>
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<tr>
<td>Agency for Healthcare Research and Quality**</td>
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<td>$334 million</td>
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* Reflects the CDC core program budget. ** Excludes funding from transfers.
Bridge Project Aims to Attack Most Lethal Forms of Cancer

Four research teams in the Boston area have been awarded grants by the Bridge Project, a clinical research collaboration between Dana-Farber/Harvard Cancer Center and Koch Institute at MIT. The goal of the collaboration is to give patients with two of the most lethal forms of cancer—pancreatic cancer and glioblastoma, a brain cancer—a better prognosis.

The collaboration is being funded by individual philanthropists Arthur Gelb and Thomas Peterson, as well as the Lustgarten Foundation and the National Brain Tumor Society.

According to a press release, the project will raise and deploy $50 million over the next three to five years to additional research teams focused on potentially transformative initiatives.

NIH Looks Ahead to Funding Rates in FY13

Because a higher number of grants than normal are expiring in FY13, the National Institutes of Health expects to be able to fund 8% more new grants and competitive renewals, even with a flat budget, according to the Nature News Blog. The downside of that number, however, is that NIH will likely fund fewer total grants than in FY12, a projected 34,252, or about 100 fewer than in FY11.

The rate at which grants are funded—which hit a historic low of 18% in FY11—is expected to increase slightly to 19%.

NIH has also taken other steps to provide new grants, including cutting 1% from FY12 levels for existing grants. NIH Director Francis Collins, MD, PhD, said those measures are not taken lightly, but he said he felt that current grantees were “willing to absorb that change.”

New Poll Data

Continued from page 1

their profession or moving abroad to countries with a stronger investment in research;
• 66% of likely voters believe government investment in medical and health research will have an impact on the future of the United States; and
• nearly 70% of Americans believe science and math education will have an impact on the future of the United States.

To view the poll, visit www.researchamerica.org/uploads/0312nationalpollwithJZA.pdf.

Organization for the Study of Sex Differences to Hold Meeting in June

The Organization for the Study of Sex Differences, a partner of the Society for Women’s Health Research and in conjunction with the International Society for Gender Medicine, is changing the face of biomedical research through the first international meeting highlighting sex and gender differences in biology, physiology and medicine June 7-9 in Baltimore.

A diverse program brings international experts to discuss topics of ethics, epigenetics, fetal programming, sex disparities in disease, and global health. Through workshops and presentations, the meeting will not only foster new interdisciplinary research but also train the future generation of biomedical researchers who will continue to advance biomedical research. Visit www.osdweb.org to register.

Special Thanks to New and Renewing Research!America Alliance Members

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American Association for Cancer Research
American Federation for Medical Research
American Public Health Association
American Society for Biochemistry and Molecular Biology
American Society for Clinical Investigation
American Society for Microbiology
The American Society of Hematology
American Society of Tropical Medicine and Hygiene Association for Psychological Science
The Association for Research in Vision and Ophthalmology
Baylor College of Medicine
Biotechnology Industry Organization
CDC Foundation
CFIDS Association of America
Drexel University College of Medicine
Albert Einstein College of Medicine at Yeshiva University
The J. David Gladstone Institutes
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Johnson & Johnson
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2012 National Health Research Forum
Battelle
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Visit www.researchamerica.org/partnership_opportunities for ways to support Research!America.
**Lilly to Begin Partnering with Academia**

Eli Lilly and Co. has announced it will spend as much as $10 million per year as part of a new initiative with university researchers to support the company’s drug discovery and development efforts.

The program, called Innovation Starts Here, has selected the first three teams that will begin work with Lilly. The Indiana University School of Medicine will help research chronic pain, while universities in Denmark and Spain will help look at schizophrenia and Alzheimer’s disease.

The Indianapolis Star notes that Lilly has had a long history of teaming up with academia. In 1923, it bought the commercial rights for insulin from the University of Toronto, which had discovered the medicine.

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**Research!America New Board Members Continued from page 1**

He has been a member of the UCSF faculty since 1976. Yamamoto was a founding editor of Molecular Biology of the Cell and was elected as a member of the American Academy of Arts and Sciences in 1988, the National Academy of Sciences in 1989, the Institute of Medicine in 2003 and as a fellow of the American Association for the Advancement of Sciences in 2002.

Six other Board members have been re-elected for another three-year term: Jay A. Gershen, DDS, PhD; Elizabeth Baker Keffer; Alan I. Leshner, PhD; Lucinda Maine, PhD, RPh; John R. Seffrin, PhD; and Elias Zerhouni, MD.

Individual members of Research!America elected Debra Lappin, JD, to a third three-year term as the representative of individual members to the Board of Directors.
The research advocate

Did you know that three of the major global health product development partnerships in the U.S. are headquartered in New York? Or that New York City has the largest bioscience workforce and second largest life sciences workforce of any U.S. city, employing 80,000 people?

On April 9, Research!America is hosting a forum in New York City to discuss how global health R&D in New York is fueling innovation and saving lives worldwide. Mary Woolley, president and CEO of Research!America, and Rep. Nita Lowey (D-NY) will make opening remarks. Influential commentator Laurie Garrett will moderate an expert panel that will showcase the contributions of innovative global health partnerships to the state’s economy. Panelists include Jack DeHovitz, MD, MPH, director, SUNY Downstate AIDS International Training and Research Program; Margaret McGlynn, president and CEO, International AIDS Vaccine Initiative; Mel Spigelman, MD, president and CEO, Global Alliance for TB Drug Development; and Pol Vandenbroucke, MD, vice president of development, emerging markets, Pfizer.

Research!America will also release a fact sheet detailing the economic impact of global health R&D in New York and the results of a state public opinion poll on the value of global health research. Please visit www.researchamerica.org/gh_newyork for more information.

FDA Gives Green Light to Georgia Lab for HIV Vaccine Trial

An Atlanta research collaboration may be one step closer to finding a vaccine that will provide long-lasting protection against repeated exposures to HIV. Scientists at Emory University and GeoVax Labs, Inc. developed a vaccine that has protected nonhuman primates against multiple exposures to simian immunodeficiency virus (SIV), the nonhuman primate version of HIV.

In March, the Food and Drug Administration granted GeoVax an “allowed to proceed” notice for a Phase 1 clinical trial, slated to begin this month. The trial is being sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health, and will be conducted by the NIAID-funded HIV Vaccine Trials Network.

A successful HIV vaccine would offer an uninfected person a high level of protection from HIV, with potential worldwide implications.

“HIV survives by being able to evade the defenses of its host. If the infection is prevented from the beginning, the virus never has the chance to embed itself in the host,” Harriet Robinson, PhD, GeoVax’s chief scientific officer and developer of the vaccine, said in a statement.

Rep. David Scott (D-GA) toured GeoVax in February and pledged his support for HIV research.

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Which of the following statements is closer to your view?

Statement A: It is important that the U.S. is a leader in medical and health research. Or Statement B: It does not matter where in the world medical and health research takes place—in today’s world, U.S. consumers will benefit regardless.

SOURCE: A RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH JZ ANALYTICS IN MARCH 2012.
Advocacy & Action

Ask Our Next President and Next Congress About the Future of Health Research

As the presidential campaigns heat up, it’s time to find out where the candidates stand on health research issues. Research!America has launched our award-winning voter education initiative, *Your Candidates–Your Health* 2012. This initiative, which can be found at www.yourcandidatesyourhealth.org, gets candidates on the record with their views on health research and displays their responses to a questionnaire on our website. Congressional primaries are beginning; as results of those primaries become known, candidates for Congress will be asked to participate.

Research to improve health is a critical issue for our nation, and Americans deserve to know where candidates stand. Together, we can put the spotlight on health research in the 2012 elections.

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World Class to Second Class?

Confronting the Risks to U.S. Science and Innovation

National Health Research Forum
I remember when Bernadine Healy was recovering from her own dreaded brain cancer, I called her up and we had a chat. I said, 'Did you read The New York Times? Breast cancer rates, because of the change in hormone therapy, has gone down 15%.' I said, 'You know Bernadine, because of the way we worked together, we worked to save lives a million at a time.' Wow. So, I tell you that story because, you see, I could go through numbers and statistics. But for me, it's always about the human. And I know each and every one of you … it's always about the people.
Scott Johnson  
**Gordon and Llura Gund Leadership Award**

“The mission of our organization is to demonstrate that medical research can be accelerated. To go from the bench to bedside, as is the common term, we can do that in a much more rapid timeframe. Leadership is about thinking differently and executing. Because doing the same thing as everyone else is the definition of following. And so everything about what we do at the Myelin Repair Foundation is different.”

Mary Jane Marchisotto  
**Paul G. Rogers Distinguished Organization Advocacy Award**

“We need more money to conduct the groundbreaking research to get us to the cure, to get us to the finish line. This evening marks an incredible milestone for FAI and for the food allergic community. Your award recognizes not only what we have done, it also validates that food allergies are a major public health issue that needs to be resolved. And while we are very, very proud of our considerable accomplishments, we are even more energized by the initiatives that we are working on today.”

Donald A. B. Lindberg, MD  
**Geoffrey Beene Budders of Science Award**

“I do take great pleasure in the moment in which we pay some attention to studies of information per se that are the basis of the practice of medicine, basis of learning, basis of remembering. It’s worthwhile to invest in research in those areas because they benefit all of us. And I think the focus that this organization has on continuing—that is to say, long-term—basic research support is tremendously important. Nothing could be better for the country, and I think for probably for the world as well.”
Raymond and Beverly Sackler Award for Sustained National Leadership
Margaret Foti, PhD, MD (h.c.)
CEO, American Association for Cancer Research

“It's really a great blessing to be able to work in the cancer field and to know that, in some small way, my work is helping people. We must never forget our patients. Our patients are waiting, and they're depending on us to do better. And they bring us their suffering, and they bring us the need to move forward. We must bring them this amazing scientific discovery that is happening. We must bring all of that to their bedsides as rapidly as possible.”

Isadore Rosenfeld Award for Impact on Public Opinion
Sanjay Gupta, MD
Chief medical correspondent, CNN

“I think we can, in a sense, use media to broaden the peer review process. I think that this is a very exciting part: broaden that peer review process so that everyone really has a voice. It can also create a more inclusive, contributing community for scientists and researchers all over the world. You never know where the next great development, the next great research is going to come from; I think media can help give a voice to lots of people, lots of labs, lots of contributors—right in this room and anywhere around the world. And I think they can make all of that happen much faster.”

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SAVE THE DATE
Advocacy Awards Dinner
March 13, 2013

To submit a nomination for the 2013 Advocacy Awards, please visit www.researchamerica.org/advocacy_awards. The deadline for nominations is May 25, 2012.

Sponsorship opportunities for the Advocacy Awards and National Health Research Forum are available. Contact Carol Kennedy, senior director, development and membership, at ckenney@researchamerica.org.
World Class to Second Class?
Confronting the Risks to U.S. Science and Innovation

Research!America’s National Health Research Forum

March 14, 2012

“I think one of the roles of media is to be skeptical, is to ask those tough questions, is to look to see in the setting of public-private collaborations and what the rules are on that collaboration... We’re not going to get anywhere without a strong public-private collaboration, but it has to be very, very clear. And it isn’t always.” —RICHARD BESSER, MD, chief health and medical editor, ABC News

“Research both helps people live longer lives by all of the work that’s done in drug discovery, new therapies and things that impact families, patients, caregivers, every single day. And research boosts the economic engine of every community that hosts academic institutions in this country.” —NANCY BROWN, CEO, American Heart Association

“I think it’s incumbent upon all of us, because we’ve all used this word, ecosystem, to make sure that students,
young people, all of us who are in the industry understand that it is not only interdependent, but it is necessary, beneficial and can be rewarding no matter where you are in that process. ... All of it needs to be done together. And it shouldn’t be competitive, but rather it should be mutually supportive. We don’t do enough of that, in my opinion.”—JOHN CASTELLANI, president and CEO, PhRMA

“Preventing health care-associated infections is reducing health care costs by billions of dollars a year. And yet there are billions more that we haven’t yet reduced, and we need to figure out how to. Take immunization: Every dollar we spend vaccinating children saves $3 of health care costs and $10 for the society as a whole ... We have much more to do in prevention, and it matters where you are in that process. ... All of it needs to be done together. And it shouldn’t be competitive, but rather it should be mutually supportive. We don’t do enough of that, in my opinion.”—JOHN CASTELLANI, president and CEO, PhRMA

Thomas Frieden, MD, MPH

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Mary J.C. Hendrix, PhD

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Margaret Hamburg, MD

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