Research!America Announces 2018 Advocacy Awards Honorees

A former congressional leader who was instrumental in doubling the National Institutes of Health (NIH) budget, the head of a global research center aimed at reducing the burden of disease, two long-time mental health advocates dedicated to accelerating research, a rare disease organization committed to biotech innovation, and a world-renowned vaccine researcher are among those who will be honored at Research!America's 22nd annual Advocacy Awards on Wednesday, March 14, 2018, in Washington, D.C. The honorees for the Isadore Rosenfield Award for Impact on Public Opinion and the Edwin C. Whitehead Award for Medical Research Advocacy will be announced in the coming weeks.

**The Honorable John Edward Porter** will receive Research!America's 2018 Legacy Award. Porter has served on Research!America's board since 2001, 12 of those years as chair and now chair emeritus. During his 21 years as the Republican Congressman from Illinois's 10th district, Porter served on the U.S. House Committee on Appropriations and chaired the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, which allocates funding for the National Institutes of Health (NIH) and other health-related federal agencies. He spearheaded the doubling of NIH’s budget during the period 1998-2003. One of the world’s largest neuroscience facilities – the John Edward Porter Neuroscience Research Center at NIH - was named in his honor.

**Roger I. Glass, M.D., Ph.D.**, director of the Fogarty International Center and associate director for international research at NIH, will receive the Geoffrey Beene Builders of Science Award for his leadership in strengthening NIH’s research and training partnerships abroad and his extensive research in the prevention of gastroenteritis from rotaviruses, noroviruses and cholera.

**Shari and Garen Staglin**, founders of the Staglin Family Vineyard, will receive the Gordon and Llura Gund Leadership Award for their commitment to accelerating cures for brain disorders through scientific research. The Staglins founded One Mind, One Mind Institute and Bring Change2Mind to address brain disorders and stigma. For the last 23 years, their annual Music Festival for Brain Health has helped raise over $280 million for brain health research.

**Shari and Garen Staglin**

**The EveryLife Foundation for Rare Diseases** will receive the Paul G. Rogers Distinguished Organization Advocacy Award for its efforts to improve the regulatory process for drug development and strengthen the patient voice. The Foundation played a pivotal role in securing passage of the bipartisan 21st Century Cures Act, which was signed into law in 2016.

**Peter J. Hotez, M.D., Ph.D.**, dean of the National School of Tropical Medicine and professor of pediatrics and molecular virology and microbiology at Baylor College of Medicine will receive the Raymond and Beverly Sackler Award for Sustained National Leadership for his important research in neglected tropical disease (NTD) and vaccine development.

Visit [www.researchamerica.org/advocacy_awards](http://www.researchamerica.org/advocacy_awards) for more information.
As we go to press, the nation remains in shock after the most deadly domestic gun massacre of our time. Our hearts go out to the families and friends of the victims even as our advocacy goes out to elected representatives, urging them to stop erecting barriers to the conduct of research that can help us better understand gun violence as a public health challenge, as well as research that will identify effective ways to put what we know to work, sooner rather than later. As a nation, we have found and adopted both common sense and policy-driven solutions to other inherently hazardous, but also valued, aspects of our lives – cars and alcohol and swimming pools, to name just a few. Right now we are struggling with opioids and guns, and as long as they stay in the headlines they will stay on the priority list of policymakers. We urge advocates to speak up and show support for the public health, behavioral and biological research that we so desperately need.

Research matters. The Lasker and Nobel prizes this year highlight the value of taxpayer-supported research and public-private partnership in speeding medical progress. Advocacy matters, too. In addition to weighing in on gun violence and opioids, we urge advocates to weigh in with their elected representatives this month to assure that the major budget decisions and tax reform discussions now underway do not shortchange policies and funding for research that will improve health, drive economic prosperity, and contribute to national security.
Opioid Epidemic Discussed at 2017 National Health Research Forum

Research and education are key to addressing the complexities of the opioid epidemic. “On the research side, it goes everywhere from understanding pain better as a neurological phenomenon to finding some non-addictive strategies for addressing pain more effectively,” said Lucinda Maine Ph.D., executive vice president and CEO, American Association of Colleges of Pharmacy. “Across the board there’s just a real lack of sufficient education for clinicians and patients and everybody else in the ecosystem at this point in time.” Maine joined experts for moderated panel discussions at Research!America’s National Health Research Forum on September 7 in Washington, D.C.

“This is touching too many families for us to be in denial, I think we have a turning point,” former Congressman Patrick Kennedy said, but added that there is a lack of interest among medical professions to provide medication-assisted treatment for opioid addiction.

Panelists agreed medical education must improve to ensure providers address opioid addiction based on the best available research. “We’re the only state in the country where you can’t graduate from medical school, dental school, nursing school or pharmacy school addiction based on the best available research. “We’re the only state in the country where you can’t graduate from medical school, dental school, nursing school or pharmacy school without taking and passing a course in opioid therapy and pain management,” said Massachusetts Governor Charlie Baker. Continued on page 4

Federal Policy Update

October is here and the first day of the month brought the beginning of fiscal year 2018. September started with a flurry of activity on Capitol Hill. On September 8, 2017, the House and Senate packaged and passed a Continuing Resolution (CR) that flat-funds government until December 8, providing supplemental disaster aid for those affected by Hurricane Harvey, and increased the federal debt ceiling.

The short-term CR gives Congress more time to plan the path forward for FY18 appropriations. The House passed a 12-bill omnibus (H.R.3354) on September 14 and sent it to the Senate. The Senate Appropriations Committee has passed most of the FY18 appropriations bills, but has yet to send any to the Senate floor for consideration.

All of the appropriations bills making their way through the House and Senate assume achieving some sort of budget deal. The House omnibus bill exceeds the FY18 defense budget cap and the pending Senate bills are above the budget caps as well. If either the House omnibus package or the 12 Senate bills were signed into law without a deal to raise the budget caps, an across-the-board spending cut would automatically be triggered to reconcile spending to the budget caps. It remains critically important to make the case for a bipartisan budget deal that raises FY18 caps on defense and non-defense discretionary (NDI) spending. On September 11 and 12, Research!America hosted a two-day digital #RaiseTheCaps initiative urging Congress to lift the FY18 spending caps, and we will continue to make the case for a budget deal as Congress considers FY18 funding legislation.

The Affordable Care Act (ACA) is still in place after the latest repeal-and-replace legislation, the “Cassidy-Graham” bill, failed to secure sufficient support to pass the Senate. The legislation would have eliminated the Prevention and Public Health Fund (PPHF) and repealed the medical device excise tax. Research!America continues to urge Congress to preserve the PPHF, which plays a crucial role in CDC’s ability to protect public health, and to end the medical device tax, which disincentivizes investment in life-saving medical technologies.

On September 26, the Senate passed their version of the FY18 National Defense Authorization Act (NDAA). The legislation included damaging provisions that place the Congressionally Directed Medical Research Program (CDMRP) at risk. However, the House and Senate still need to reconcile differences between their two versions of the NDAA bill through “conference” negotiations, and each pass the compromise bill. Research!America sent a letter to House Armed Services Committee Chairman Mac Thornberry (R-TX-13) and Ranking Member Adam Smith (D-WA-9) urging them to oppose the damaging CDMRP provisions, and reject language in the accompanying report that would compromise the integrity and effectiveness of DoD’s technology transfer program.
As the opioid epidemic continues to intensify, innovative research provides much needed hope to alleviate the suffering of the tens of thousands of Americans coping with this addiction. About 60% of Americans support increased funding for research to better understand and combat opioid addiction, according to a public opinion survey commissioned by Research!America.

The webinar, “Innovating Research and the Opioid Epidemic: Are We Closer to Finding Solutions?,” will be hosted by Research!America on Friday, October 13, 2:00-3:00 p.m. ET.

Confirmed speakers are Nora Volkow M.D., director, National Institute on Drug Abuse at the National Institutes of Health; Georges Benjamin, M.D., executive director, American Public Health Association, and Research!America board member; and Jeffrey Bratberg, Pharm.D., clinical professor, University of Rhode Island College of Pharmacy.

The discussion will focus on the role of research in combatting the opioid crisis, public health implications and the role of pharmacists in addressing the epidemic.

For more information and to register, visit http://bit.ly/2wsPN4b.

Anne Schuchat, M.D., principal deputy director, Centers for Disease Control and Prevention, said the CDC issued guidelines for prescribing for chronic pain “that was really about think twice before you start one of these medicines. We’ve had a huge response to the guideline. Medical schools, residency training, nursing schools, pharmacy schools” have adopted them into their core curriculum.

In his remarks, Scott Gottlieb, M.D., commissioner, Food and Drug Administration (FDA), said the agency is exploring abuse-deterrent drug formulations, medically-assisted therapies and non-addictive pain products. “In order to reduce addiction, we need to reduce exposure. And the way we’re going to do that is to make sure fewer prescriptions are written.”

Prevention strategies are necessary to curb the rate of addiction, speakers noted. “The balance between prevention and intervention is a key part of both public and medical policy, and unfortunately the U.S. has not been the most active country in having enough preventive programs,” said Mikael Dolsten, M.D., president of worldwide research & development, Pfizer.

“If you want to reduce illness, it’s better not to have it happen in the first place,” said Francis Collins, M.D., director, National Institutes of Health. William N. Hait, M.D., global head, Janssen Research & Development, LLC, Janssen Pharmaceutical Companies of Johnson & Johnson, noted that prevention is critical in order to make significant progress in reducing disease prevalence. The program featured panel discussions with top leaders in government, industry, patient advocacy and academia. For more on the event, visit www.researchamerica.org/forum.

Experts Discuss Translating Alzheimer’s Research into Clinical Practice at Congressional Briefing

With the number of Americans living with Alzheimer’s disease, about 5.5 million, expected to triple by 2050, this illness imposes a staggering societal and economic toll on the nation. Research!America invited experts in medical research, public health and disease advocacy to discuss how recent insights in Alzheimer’s research shed new light on the prevention and treatment of this devastating condition during an October 5 Capitol Hill Briefing titled “From Discovery to Delivery: Research at Work in Alzheimer’s Disease.”

Although federal funding for Alzheimer’s remains strong, the panel discussed the difficulties of translating research into clinical practice when Alzheimer’s goes long undetected before massive nerve cell loss leads to physical and cognitive decline. Though a cure may be far off, panelists reiterated that prevention should be a major public health focus.

“We have to teach people that they are responsible for their own health,” urged Rosebud Roberts, M.D., Ch.B., chair of the Mayo Clinic Division of Epidemiology, noting that lifestyle choices increase Alzheimer’s risk. Richard Hodes, M.D., director of the National Institute on Aging, and Michael Irizarry, M.D., MPH, vice president of early clinical development, neurosciences, at Eli Lilly, emphasized that monitoring non-symptomatic but high-risk individuals may reveal early biomarkers of the illness and provide insights into the molecular basis of disease progression.

Other panelists included Julie Zissimopoulos, Ph.D., associate professor in the Sol Price School of Public Policy at the University of Southern California and Shawn Taylor, founder and president of VeteransAgainstAlzheimers. The panel was moderated by Robert Egge, chief public policy officer and executive vice president of government affairs, Alzheimer’s Association.

Federal Research Budget

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* indicates that program level is reported in this chart
** indicates that budget authority is reported in this chart
National Health Research Forum


Research!America board member Lucinda Maine, Ph.D., R.Ph., executive vice president and CEO of the American Association of Colleges of Pharmacy, and a panelist at the Forum, was featured in an WebMD article about the role of pharmacists in curbing the opioid epidemic.

Fogarty Center Essential to Global Health

Research!America Chair Emeritus The Honorable John Edward Porter penned an editorial for The American Journal of Tropical Medicine and Hygiene highlighting the significant contributions of the Fogarty International Center in saving lives and training the next generation of scientists.

Social Science Support

Research!America president and CEO Mary Woolley’s editorial for the Why Social Sciences blog underscores the value of social and behavioral research. “By fostering a better understanding of human behavior, preferences, and motivations, social and behavioral research reveals new strategies for achieving optimal health outcomes.”

NIH Funding

An article in The Scientist about the Senate Labor-HHS appropriations approval of a $2 billion increase to the National Institutes of Health budget featured a statement from Mary Woolley.

Clinical Trials

In an Outsourcing Pharma article, Research!America’s vice president of communications Suzanne Ffolkes shared insights from a recent Research!America commissioned survey of perception of clinical trials among minority populations. The survey results were also featured in STAT, The Clinical Leader and other publications.

United National Health-Related Sustainable Goals

In a CNN article about a report from The Lancet regarding the progress nations are making to reach global health-related sustainable development goals by the year 2030, Research!America board member Georges Benjamin, M.D., executive director, American Public Health Association, commented on the challenges and opportunities for achieving the goals.

Smoking and Cancer

Research!America board member Gary Reedy, chief executive officer, American Cancer Society, was quoted in a Drug Store News article about the Society’s partnership with the CVS Health Foundation to create tobacco-free U.S. colleges and university campus environments to reduce the number of deaths from cancer and other tobacco-related diseases.

DACA and Health Care

Research!America board member James Madara, M.D., EVP and CEO, American Medical Association, sent a letter to Congress about the consequences of ending the Deferred Action for Childhood Arrivals (DACA) program on the U.S. health care system, which was featured in a CNN article.

IN BRIEF

- The Food and Drug Law Institute (FDLI) is hosting Patient Organizations: An Introduction to U.S. Drug Law and Regulation, November 7-8 in Washington, D.C.
- Applications are being accepted for the 2017 Leshner Leadership Institute Fellowship through November 1.
  leshnerfellows.aaas.org
- The National Academy of Medicine published a report developed at the request of the National Governors Association to assist the nation’s governors as they work with clinicians to counter the opioid crisis.
  http://bit.ly/2x5g1Pi
- Constance E. Lieber is the recipient of the 2017 Honorary Pardes Humanitarian Prize in Mental Health, which will be presented posthumously in New York City on Friday, October 27.
West Virginia Research and Innovation

Medical and health research has enormous potential for addressing community health threats such as the opioid addiction and building a strong science and technology hub. Leaders from government, industry, academia, and scientific societies will discuss the role of public and private sector research in supporting the local economy and improving the health of citizens in West Virginia at a forum on Monday, October 16 on the campus of Shepherd University in Shepherdstown, West Virginia.

Senator Joe Manchin (D-W.Va.) and Senator Shelley Moore Capito (R-W.Va.) will open the program, titled “West Virginia Research and Innovation: A Catalyst for Better Health and Economic Growth,” along with Brad Fenwick, Ph.D., senior vice president of global strategic alliances, Elsevier. The forum panel will be moderated by Judy Miller Jones, founding director, National Health Policy Forum. Panelists include: Rear Admiral James C. “Jim” Olson, USCG (ret.), U.S. interdiction coordinator, Office of National Drug Control Policy, Executive Office of the President; Marcia K. Brand, Ph.D., senior advisor, Dental Quest Foundation; Fred White, senior director of business development, ABS Consulting; Cannon Wadsworth, director, state and commercial programs, Global Science & Technology, Inc.; and Dr. Fenwick. The panel discussion will focus on the role of research in curbing the opioid crisis, improving health outcomes in rural Appalachia, West Virginia’s knowledge economy and private sector innovation in the state.

Research!America’s president and CEO Mary Woolley will also present key findings of a new survey of West Virginians on medical and health research. The program will be live-streamed at www.shepherd.edu/research-america.

Salute Public Health Professionals on November 20

On the Monday before Thanksgiving, November 20, Research!America and partners will recognize public health professionals who are on the front lines and behind the scenes protecting Americans from disease, injury, and other health threats.

During the weeks leading up to PHTYD, Research!America will highlight themes related to public health. The first theme week, October 23-27, will explore facets of public health and highlight initiatives that impact where we live, work, and play. October 30 - November 3 will focus on how public health professionals respond to current and emerging health challenges at the local, national, and global levels.

The third week, November 6-10, will shine a spotlight on innovations in public health that aim to address disparities in care and ensure that all Americans have access to quality, affordable and evidence-based care. The final week, November 13-17, asks us to imagine a life without disease, and will feature new technologies that are rapidly driving medical innovation, from advances in disease therapies to progress in health IT.

Visit www.publichealththankyouday.org to learn more and become a partner in thanking public health professionals on November 20.

Rising Stars in Pharmacological Sciences Learn about the Importance of Research Advocacy

In order to elevate public appreciation for the role of medical and health science in advancing public health and medical progress, academic researchers must play an active role in science communication, public engagement and advocacy.

Research!America President and CEO Mary Woolley spoke about the challenges and importance of advocating for research during a presentation on September 25 before the American Association of Colleges of Pharmacy (AACP) Catalyst Leaders of 2017. This audience consisted of distinguished mid-career investigators in the pharmacological sciences enrolled in a selective professional development program to expand research and leadership capacity.

During her seminar, Woolley highlighted how public engagement and advocacy are vital for continued and robust federal investments in biomedical science. “You can’t outsource advocacy,” Woolley insisted. “It belongs to the research community.” In encouraging the audience to, “tell your story and not your data,” Woolley shared her insights on why failing to engage in advocacy can be detrimental to science careers, tips on how to articulate the value of research to those with non-scientific backgrounds, and strategies to establish trust with diverse audiences.
The Patient-Centered Outcomes Institute (PCORI) is a private nonprofit organization authorized by Congress to fund research that helps people make informed health care decisions and improves health care delivery and outcomes. It does so by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

When confronting a significant health care issue, patients, their families, and their clinicians can face an array of complex, sometimes-confusing choices about possible treatment options. They need trustworthy, useful information to decide which choice might work best in their situation.

Unfortunately, traditional health research, for all the remarkable advances it produces, hasn’t been able to answer many of the questions patients and their clinicians face daily. The Patient-Centered Outcomes Research Institute (PCORI), an independent nonprofit organization in Washington, D.C., was authorized by Congress in 2010 to address that problem.

PCORI’s mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decisions. PCORI does this by funding comparative clinical effectiveness research (CER) studies that assess which of several available prevention, diagnosis, or treatment approaches works best for whom, considering outcomes that matter to patients.

What makes PCORI unique is its commitment to ensuring meaningful involvement by patients, caregivers, clinicians and other health care stakeholders throughout the research process—from selecting the topics to study through designing and conducting the research itself and disseminating results. PCORI takes this approach so that the resulting evidence addresses stakeholders’ most important questions and concerns.

“By involving stakeholders from the start, PCORI believes the projects we fund will focus on the right questions, use the right methods, and produce results that are more useful than traditional research findings, and so more likely to be taken up in practice,” says PCORI Executive Director Joe Selby, M.D., MPH. “And we’re starting to see the benefits of this approach in the growing number of PCORI-funded studies reporting important results in the medical literature.”

To date, PCORI has approved nearly $2 billion in funding for more than 600 patient-centered CER studies and related projects to enhance the methods and infrastructure that support such research. PCORI pays particular attention to conditions that impose a heavy burden on individuals, their families, and the healthcare system as a whole, including chronic and rare or understudied conditions.

PCORI also provides awards to encourage engagement of patients and other health care stakeholders in the research process, helping to build a broad community that can support PCORI’s work and help ensure that clinical research and the health care system overall can become more patient-centered and effective.

“This is one of the many reasons that PCORI is proud to be a member of Research!America,” Selby says. “We fully share Research!America’s core commitment to improving health by supporting a high-quality research enterprise and raising awareness of the importance of scientifically rigorous research.”

For more information, visit www.pcori.org.

Nearly Three-Quarters Say Doctors Don’t Talk About Medical Research

Has your doctor or other health care professional ever talked to you about medical research?

- Yes: 27%
- No: 48%
- Not Sure: 15%
- Don’t Know: 1%

Source: A Research!America survey of U.S. adults conducted in partnership with Public Policy Analytics in July 2017. Due to rounding, the total may not add to 100%.
Urge Congress to #RaisetheCaps

As Congress begins to negotiate the federal budget for fiscal year 2018 (FY18), the austerity level “sequestration” budget caps established under the 2011 Budget Control Act are once again in force after a partial, two year reprieve. Unless Congress negotiates another agreement to lift these draconian caps, the FY18 budget for non-defense agencies and programs will be constrained to a level even lower than in FY17. Under that kind of stifling spending limit, Congress simply cannot fulfill its responsibility for advancing the health and wellbeing of the American people, including continuing to rebuild the long-neglected budget of the NIH, equipping the CDC to combat deadly infectious health threats and ensuring our other health and research agencies meet their respective missions.