Senator Susan Collins (R-ME) says she has witnessed the power of medical research to transform lives. In remarks at Research!America’s Advocacy Awards Dinner, she described how advances in research dramatically improved the quality of life of a young diabetes patient. “There’s no investment that promises greater returns for Americans than our investments in biomedical research,” she said. Sen. Collins received the Edwin C. Whitehead Award for Medical Research Advocacy for her leadership in advancing medical research, particularly Alzheimer’s disease and diabetes research, at the dinner held Wednesday, March 14 in Washington, D.C.

Research!America Chair Emeritus The Honorable John Edward Porter, recipient of the Legacy Award, generously supported by Ann Lurie, noted that science is too often ignored by the public and policymakers. “What worries me most today is that we have learned how to make progress with evidence-based decision-making and yet many of our fellow citizens reject this,” he said. The award has been renamed in his honor.

Dr. Peter Hotez, who was honored with the Research!America Advocacy Award for Sustained National Leadership, discussed challenges with creating a sense of urgency about neglected tropical diseases (NTDs). “We now estimate that there are 12 million Americans living in extreme poverty infected with NTDs and this has been one of the hardest advocacy efforts of all—making people care about the poor and disenfranchised right here at home.”

The annual meeting also featured a panel discussion about the latest developments in mental health research and potential new treatment targets. MedPage Today news editor Joyce Frieden moderated. Dr. Linda Brady, director, Division of Neuroscience and Basic Behavioral Science, NIMH said one of the institute’s goals is to reduce the suicide rate by 20% by 2025. “There have been a lot of initiatives rolled out of the NIMH including [mental health] screenings in the emergency department settings.”
Advocacy has proven its worth once again in helping secure increases for federal agencies including the unprecedented $3 billion boost for the National Institutes of Health in the FY18 omnibus bill. House Democratic Leader Nancy Pelosi, who joined us at our Advocacy Awards Dinner in March (see coverage elsewhere in this issue), announced the likely NIH increase in her remarks at the event, to the delight of all in the room! Just days later, President Trump signed the legislation and all federal science agencies received a much-needed boost. Yes, advocacy works but a new threat could roll back efforts to advance scientific progress.

The President and House Majority Leader Kevin McCarthy are considering employing a provision in a 1974 law that would allow cuts — known as rescissions — to discretionary spending in the just-passed omnibus bill. We cannot turn a blind eye to a threatened action that could hamstring research and public health initiatives supported by NIH, CDC, FDA, NSF and AHRQ. It is important for all the stakeholders in research to stay on top of this possibility for trouble and be ready to act. (Watch our website and look for alerts!).

Meanwhile the FY19 appropriations process is underway, and requires advocacy as well if we are to keep the momentum going in the science that drives medical progress, keeping our nation healthy, prosperous and secure. Please join us in taking a few moments to weigh in with your elected representatives to make your priorities known. And be sure to March for Science in Washington, D.C. or any number of cities and towns around the nation on April 14.

Research!America Extends Special Thanks to our Supporters who Have Contributed Since the Publication of our March Newsletter

**2018 Advocacy Awards**
- Ann Lurie
- Emil and Jenny Kakkis on behalf of the EveryLife Foundation
- EXL Service Holdings
- George Washington University
- School of Medicine and Health Sciences
- Hogan Lovells
- Lilly

**2018 Advocacy Awards (cont.)**
- Mary Woolley
- One Mind Institute
- Pfizer Inc
- Rogers Family Foundation
- Sanofi
- University of California San Francisco

**2018 Health Research Forum**
- Pfizer Inc

**Raise the Caps**
- American Educational Research Association
- Program Support
- Association of American Cancer Institutes
- Society for Neuroscience
- Takeda Pharmaceuticals

Visit [www.researchamerica.org/partnership_opportunities](http://www.researchamerica.org/partnership_opportunities) for ways to support Research!America.

**Special Thanks to New and Renewing Research!America Alliance Members**

**New Members**
- Texas A&M University
- University of Miami School of Nursing and Health Studies

**Renewing Members**
- Albert Einstein College of Medicine
- Alnylam Pharmaceuticals
- Alzheimer’s Association
- American Association for the Advancement of Science
- American Association of Colleges of Nursing
- American Association of Pharmaceutical Scientists
- American Institute for Medical and Biological Engineering (AIMBE)
- American Society for Biochemistry and Molecular Biology
- American Society for Clinical Investigation
- American Society for Microbiology
- Association for Women in Science
- Association of Schools and Programs of Public Health
- Buck Institute for Research on Aging
- Cleveland State University
- Dana-Farber Cancer Institute
- Drexel University
- Fred Hutchinson Cancer Research Center
- Gates Center for Regenerative Medicine
- George Washington University School of Medicine and Health Sciences
- Gladstone Institutes
- Greater Akron Chamber
- Kidney Cancer Association
- Lilly
- Mayo Clinic
- Melanoma Research Alliance
- National Patient Advocate Foundation
- NewYork-Presbyterian Hospital
- New York Stem Cell Foundation
- North American Vascular Biology Organization
- North Carolina Association for Biomedical Research
- Pfizer Inc
- PhRMA
- Scleroderma Foundation
- Sjogren’s Syndrome Foundation
- Takeda Pharmaceuticals
- The ALS Association
- The Leukemia & Lymphoma Society
- The University of Texas Health Science Center at San Antonio
- University of North Carolina School of Medicine
- University of Virginia Health System
- U.S. Pharmacopeial Convention
- Vanderbilt University Medical Center
- WomenHeart: the National Coalition for Women with Heart Disease

Not yet a member? Join Research!America today at [www.researchamerica.org/membership](http://www.researchamerica.org/membership). As of April 5, 2018
Advocacy Awards continued from page 1

Other honorees included Shari and Garen Staglin, who received the Gordon and Lura Gund Leadership Award for their efforts in brain disorder research advocacy. Dr. Atul Gawande, bestselling author and professor at Harvard Medical School, received the Isadore Rosenfield Award for Impact on Public Opinion for raising public awareness about the standard of health care. The Paul G. Rogers Distinguished Organization Advocacy Award was presented to The EveryLife Foundation for Rare Diseases. Emil Kakkis, founder and board member of the Foundation, and Max Schill, patient advocate, accepted the award on the Foundation’s behalf. Dr. Roger Glass received the Geoffrey Been Builders of Science Award for his leadership as director of the Fogarty International Center at the National Institutes of Health. For videos, photos and a special insert from the 2018 Advocacy Awards Dinner, visit http://bit.ly/2JnpQde.

Annual Meeting continued from page 1

Dr. Wayne Drevets, scientific vice president and disease area leader, mood disorders, Neuroscience Therapeutic Area, Janssen Research & Development, said promising new studies of biomarkers could help doctors better zero in on effective treatments for individual patients.

Many advances in how doctors treat psychiatric conditions involve both neuroscience and engineering, said Dr. Kafui Dzirasa, associate professor of psychiatry and behavioral sciences, Duke Institute for Brain Sciences. “That is happening in terms of constructing new tools and devices to get information out of the brain at the speed at which thoughts happen.” One Mind president and patient advocate Brandon Staglin encouraged advocates to learn all they can about the amazing science that’s changing brain health and to share that information with family, friends and lawmakers. Watch a recording of the event at http://bit.ly/2q4j1fL.

Federal Policy Update

On March 23, Congress passed and President Trump signed the 2018 Consolidated Appropriations Act, which provides an unprecedented $3 billion funding increase for the National Institutes of Health (NIH), as well as meaningful funding increases for CDC, NSF, FDA, AHRQ and our nation’s other health and science agencies. These increases in part reflect funding dedicated to addressing the opioid crisis, advancing a universal flu vaccine, and bolstering the resources available for Alzheimer’s research, the BRAIN initiative, antibiotic resistance countermeasures, the cancer moonshot, and the All of Us research initiative. The spectrum of science-related funding increases is a testament to our work together as an alliance and as part of the broader science community; joining together, we ensured science was assigned the priority it merits as the path to better health, a stronger economy and a safer world.

With respect to the policy impact of the bill, notably absent is any language that restricts fetal tissue research. Research!America has been working closely with the Coalition for Cell Biology to ensure that proposed riders to limit such research were not enacted in the final omnibus. Congress did include language in the bill that prevents the administration from making any modification to indirect cost calculations. Also included was language that affirms the CDC’s authority to conduct research on the causes of gun violence. As with any public-health threat facing our nation, Research!America has repeatedly called for evidence-based solutions based in rigorous research.

Even as FY18 budget negotiations were wrapping up, members of Congress were setting deadlines for FY19 appropriations requests. In addition to a targeted campaign of requests that sought to build champions for our health and science agencies in both chambers, we worked closely with Congressman Don Beyer (D-VA) in drafting a “Dear Colleague” letter in support of AHRQ. Combined with separate sign on letters we joined for NIH, NSF and AHRQ, these tools are an important component in making the case for sustained and robust funding.

The opioid crisis continues to receive attention in both the White House and Capitol. President Trump held an “Opioid Summit” this month to discuss his administration’s plans to address the epidemic. On the other end of Pennsylvania Ave., both the House and Senate are beginning to put forth legislation aimed at curbing the crisis. Earlier this month, AHRQ refined its hospital data resource to provide county-level statistics on opioid-related hospitalizations. This came at the same time CDC reported a 30% increase in hospitalization rates from July 2016 to September 2017. With this public-health emergency showing no signs of slowing, we will continue monitoring any proposed legislation and call for initiatives that effectively save lives and treat the underlying causes of addiction.
Prominent HIV/AIDS Researcher Chosen to Lead CDC

Dr. Robert Redfield, a virologist and physician who is well-known for his extensive work in the area of HIV/AIDS, has been appointed the new director of the Centers for Disease Control and Prevention (CDC). In a speech to CDC staff, Dr. Redfield said the agency is “science-based and data-driven, and that’s why CDC has the credibility around the world that it has.”

A member of the President’s Advisory Council on HIV/AIDS from 2005 to 2009, Dr. Redfield also led an extensive clinical program providing HIV care and treatment to 6,000 patients in the Baltimore/Washington, D.C. area. He was founding director of the Department of Retroviral Research within the U.S. Military’s HIV Research Program.

“Dr. Redfield has dedicated his entire life to promoting public health and providing compassionate care to his patients, and we are proud to welcome him as director of the world’s premier epidemiological agency,” said U.S. Department of Health and Human Services Secretary Alex Azar in a statement.

Dr. Redfield served as Chief of Infectious Diseases and Vice Chair of Medicine at the University of Maryland School of Medicine and co-founded the University of Maryland's Institute of Virology.

You can follow him on Twitter at @CDCDirector.

Upcoming Webinars on Migraine Research and Inspiring Science Advocates

Nearly one in four U.S. households include someone with migraine, but despite the prevalence of this neurological disease, few effective treatments are available for patients. Research!America will host the webinar, “What are the Barriers in Advancing Migraine Research?” on Wednesday, April 11, 3:00-4:00 p.m. ET. Experts will discuss opportunities in accelerating the pace of migraine research, clinical research and efforts in the public and private sector to develop new treatments for migraine sufferers. Speakers include Dr. Michael L. Oshinsky, program director, pain and migraine, NINDS/NIH; Dr. Jan Lewis Brandes, Nashville Neuroscience Group; and Dr. Robert Shapiro, Department of Neurological Sciences, Larner College of Medicine at the University of Vermont. The webinar is supported in part by Amgen.

The Society for Neuroscience and Research!America will host the third webinar in a series of four on Wednesday, April 18, 1:00-2:00 p.m. ET titled “Inspiring Others to be Science Advocates.” Speakers will share insights and tips on building and maintaining relationships with communities through creative programs to foster greater interaction between scientists and non-scientists and engage them in public events such as Science on Tap and Nerd Nite in support of science. Speakers include Dr. Monica Linden, senior lecturer at Brown University; Cynthia Gibbs, founder and director of Science Pub RVA; and Dr. Rick Karnessky, co-boss, Nerd Nite East Bay.

For more information and to register for the webinars, visit http://bit.ly/2JmdjH5.

2018 March for Science- April 14

On Saturday, April 14, 2018, scientists and science enthusiasts across the globe will gather for the March for Science, the second annual celebration of science and its impact on society. Participants will urge policymakers to enact evidence-based policies that serve all communities and advance scientific knowledge. “Last year the goal was to get people out in support of science,” said Caroline Weinberg, one of the founders of the March for Science and the interim executive director of the organization in a Science magazine article. “This year we trying to put more emphasis on direct advocacy.”

The event on the National Mall in Washington, D.C. will include teach-in and poetry tents and a program featuring leaders in science advocacy. The March will be preceded by a Day of Action on Friday, April 13, with advocates contacting their representatives and visiting federal and local offices to urge policymakers to assign a high priority to science. According to a survey commissioned by Research!America, a strong majority of Americans (81%) say it is important for scientists to inform elected officials about their research and its impact on society.

Research!America President and CEO Mary Woolley and former policy fellow Dr. Anna Hatch described the benefits of scientific discovery in a video that was shown at the 2017 March for Science on the National Mall. Research!America has joined other partners for the 2018 March including the American Association for the Advancement of Science, Society for Neuroscience, Sigma Xi, the Scientific Research Society and the American Society for Cell Biology. To read more about the event, visit www.marchforscience.com.

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
Political Divide

Research!America Board Chair The Honorable Michael N. Castle called for more bipartisan cooperation among members of Congress in a Delaware State News article about the impact of political partisanship on the legislative progress. “The bottom line is we are not making the progress that we should in terms of working out legislation for the betterment of the country.”

Patient Care

In a Baltimore Sun article about University of Maryland (UMD) School of Medicine Match Day, Research!America board member E. Albert Reece, M.D., Ph.D., MBA, UMD executive vice president for medical affairs, distinguished professor and dean, encouraged students to view their careers as service to others. “Each and every patient deserves your full attention, your deepest respect and excellent care.”

Research Advocacy and Funding

Research!America Board Chair Emeritus The Honorable John Edward Porter shared insights about National Institutes of Health (NIH) appropriations, advocacy for research and the importance of engaging with candidates in a wide-ranging interview in The Cancer Letter. “I think the people who support NIH should be out there going to the town hall meetings, going to the campaign meetings, and asking the questions. Do you support NIH funding and how strongly? Put them on the spot. That seems to be extremely important.”

Mary Woolley, president and CEO, Research!America was profiled in the Roanoke Times about the recent funding increase for the National Institutes of Health and her keynote presentation on research advocacy at the Virginia Tech Carilion Research Institute. Following the passage of the FY18 omnibus spending bill, Woolley was quoted in CQ Roll Call, The Scientist, and U.S. News & World Report, applauding funding increases to the NIH and other research agencies. Research!America Vice President of Communications Suzanne Ffolkes was also quoted about the funding boost in Vox, Houston Business Journal and Albany Business Review.

Gun Violence Research

In an NPR article about gun violence research, Research!America board member Georges Benjamin, M.D., executive director, American Public Health Association, said that the recent budget language change will make gun violence research more permissible.

FDA and Tobacco Use

Research!America board member Nancy Brown, CEO, American Heart Association, was quoted in an NBC News article encouraging the FDA to develop product standards for flavored tobacco. “There is already clear evidence that flavored tobacco products, including menthol, harm the public health.”

Science Candidates

Research!America board member Rush D. Holt, Ph.D., CEO, American Association for the Advancement of Science (AAAS), told The Washington Post that candidates with STEM backgrounds would be beneficial to policymaking.

IN BRIEF

- The National Organization for Rare Disorders (NORD) announced honorees for the 2018 Rare Impact Awards, presented on May 17 in Washington, D.C.
- Dr. Ann Cary has been appointed chair of the the American Association of Colleges of Nursing (AACN) Board of Directors.
- The Pew Research Center released a report “The Science People See on Social Media,” in an effort to better understand the science information that social media users encounter.
  https://pewrsr.ch/2JnQzpV
- Research!America board member Dr. Lucinda Maine was honored with the Leadership Mentor Award at the American Pharmacists Association Annual Meeting.
Incorporating the Patient Perspective in R&D

The benefits of patient-reported outcomes (PROs) include addressing unmet needs, facilitating better decision-making across every aspect of the R&D process, and aligning care priorities with diverse patient populations. FasterCures executive director Tanisha Carino moderated a webinar on March 22, titled “Patient-Centered Measurement: How Close Are We?,” with experts representing government, research and patient groups tracking progress in integrating patients as partners in R&D.

Ellen Schultz, a senior researcher at American Institutes for Research (AIR) said patient-centered measurement is “driven by the patients’ expressed preferences, needs and values that inform progress toward better health, better care, and lower costs.”

The Michael J. Fox Foundation (MJFF) is leveraging patient data through Fox Insight, an online clinical study gathering a sample of people worldwide with and without Parkinson’s disease. “Patients are the real experts. They live with their conditions 24/7, and they have insights to share,” said Catherine Kopil, director of research partnerships at MJFF. Kopil recommended a “patient-centric model where stakeholder decisions are grounded in patient input.”

Paul Kluetz, acting associate director of patient outcomes in the Oncology Center of Excellence (OCE) at the U.S. Food and Drug Administration, noted the importance of continuity in measurement. The OCE’s Patient-Focused Drug Development initiative strives to assess the full patient experience, including improvements or declines in quality of life, and determine how stakeholders can use this information to their benefit.

Cynthia Grossman, director of science of patient input at FasterCures, said adoption of patient-centered PROs along with defining the return on investment and celebrating successes will help to advance the patient perspective in R&D.


National Public Health Week Forum – Building Better Partnerships for our Healthiest Nation

U.S. Surgeon General Jerome Adams says his vision is for a healthier and more equitable America but we must reframe the way we talk about health to achieve that goal. “I believe with every fiber of my being that every American deserves to live a long and healthy life. Unfortunately, we’re falling short of that goal.”

Dr. Adams was the keynote speaker at a forum hosted by the American Public Health Association (APHA) in Washington, D.C. on April 2 to kick off National Public Health Week. He noted that life expectancy in the U.S. has declined for a second year in a row but said better partnerships between public health professionals and local communities can improve health outcomes. “We can have a tremendous impact if we focus less on what we don’t have, and focus more on better engaging partners.”

Dr. Adams and the panel were introduced by APHA Executive Director and Research!America board member Dr. Georges Benjamin. The panel included Dr. Wendy Ellis of the Milken Institute School of Public Health; Jen Schweer of Georgetown University; Sinsi Hernandez-Cancio of Families USA; Alyse Sabina of the Aetna Foundation and was moderated by APHA President Dr. Joseph Telfair. The panel agreed that community resilience is key to addressing adverse events such as the opioid and obesity epidemics.

“And when we say resilience, we don’t mean bouncing back from trauma to return to the same broken system,” Dr. Ellis clarified. “Instead, it’s springing forward to move beyond adverse environments.” Panelists said while additional funding could help tackle public health crises, collaboration with the communities that public health experts serve is vital to sustainable results. “Health does not happen inside of a doctor’s office or inside of the clinic,” added Hernandez-Cancio. “Health happens in communities.”
Horizon Pharma focuses primarily on the research, development and commercialization of medicines that treat rare diseases, which are diseases that impact fewer than 200,000 people in the United States. Because so few individuals are affected by a single rare disease, working to better understand the nature of the specific disease as well as developing appropriate biomarkers, diagnostics and treatments is often very challenging and requires a network of academic, government and private physicians and scientists to work together alongside those few patients impacted by the disease.

Ninety-five percent of the more than 7,000 different rare diseases do not yet have a FDA-approved treatment. However, it is not sustainable or scalable to approach discovery one medicine or one disease at a time nor is it feasible for every institution to build the capabilities needed to be successful. Horizon Pharma works tirelessly to ensure that the patient perspective is the primary force driving the drug development process and regulatory decision-making.

As a company dedicated to meeting unmet medical needs, specifically in the rare disease space, Horizon Pharma understands and embraces the importance of increasing research efforts to develop therapies for some of the most vulnerable patient populations. “For us, it’s personal in that we work every day to put patients and their families first in every decision that we make including our goal to bring innovative therapies to market,” said Shao-Lee Lin, M.D., Ph.D., executive vice president, head of research and development and chief scientific officer, Horizon Pharma plc.

A common challenge for researchers and developers of rare disease therapies, Dr. Lin explained, is the small patient populations affected by these diseases. Improvements to the regulatory system/framework will be important to keep pace with scientific developments. For example, the ability to use novel methods in clinical trials, such as real world evidence and patient-focused drug development, may help get new therapies to patients faster.

“A robust research enterprise and strong investment environment affects everyone in the biomedical ecosystem,” noted Dr. Lin. “Guaranteeing well-funded federal research agencies and ensuring that policies are in place that encourage investment in the biopharmaceutical industry will allow innovative therapies to reach the patients that need them most.”

As Horizon Pharma actively seeks to address unmet needs in challenging and rare diseases, the company pursues opportunities to work across industry, academia and institutions to advance research and elevate the importance of funding to further innovative research.

“A major challenge in advocacy is making sure your voice is heard,” Dr. Lin said. “Because of this, it’s important to work with other organizations that share a common goal.” Horizon Pharma has partnered with a number of organizations, such as NORD and Global Genes, to advocate on behalf of the rare disease community. “We work with a number of umbrella organizations, such as Research!America and the Alliance for a Stronger FDA, to advocate for robust funding of America’s research enterprise,” Dr. Lin added.

For more information about Horizon Pharma, visit www.horizonpharma.com.
Congress recently completed an appropriations bill for fiscal year 2018 (FY18) that included meaningful and crucially important budget increases for our nation’s science and health agencies. The president signed the legislation into law on March 23, 2018.

The Trump Administration and House majority leadership are reportedly considering whether to pursue retroactive cuts to the new appropriations law that would target non-defense discretionary spending. Such an effort, if successful, could mean cuts to NIH, FDA, CDC, NSF, AHRQ and other agencies leveraging research to speed medical and public health progress.