Nominations Open for Herbert Pardes Family Award for National Leadership in Advocacy for Research

Research!America has announced the Herbert Pardes Family Award for National Leadership in Advocacy for Research, which recognizes individuals who, throughout their careers have – like Research!America board member Dr. Herbert Pardes – demonstrated distinguished leadership and sustained commitment to public engagement and advocacy for research. Individuals selected for this honor will be those who are highly regarded for their ability to communicate the value of research and innovation to a broad array of audiences, and who, by dint of their example and active encouragement, have inspired others to do so.

Nominations for the award are due by Friday, August 3 and should be submitted at www.researchamerica.org/PardesAward. The award will be presented at Research!America’s Advocacy Awards Dinner on March 13, 2019 in Washington, D.C. Honorees for the Pardes award and other advocacy awards will be announced in the fall.

Dr. Pardes, executive vice chairman of the Board of Trustees, NewYork-Presbyterian Hospital, is nationally recognized for his broad expertise in education, research, clinical care and health policy. He is an ardent advocate of academic medical centers, humanistic care and the power of technology and innovation to transform 21st-century medicine. Under his leadership, NewYork-Presbyterian became one of the most highly regarded and comprehensive health care institutions in the world. The hospital is top-ranked in the New York metropolitan area and is consistently ranked among the best academic medical institutions in the nation, according to U.S. News & World Report.

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Strong Majority say it’s Important for U.S. to be Global Leader in Research

How important do you think it is that the U.S. is a global leader in research to improve health?

- Very important: 67%
- Somewhat important: 26%
- Not too important: 1%
- Not at all important: 2%
- Don’t know: 2%

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Mid-summer offers no let-up in the pace of policymaker action on key legislation impacting medical and health research, and we are fully engaged. The good news is that Congress is favorably disposed to supporting research and innovation in both public and private sectors; the bad news is that there are other things on congressional plates as well, which, combined with pressures of election season, could push our interests down in terms of priorities. Our community’s recent success in standing down the rescissions package is the most recent evidence that advocacy works – and it will work again if we all rally to press Congress to act now to support research.

Advocacy works because individuals stand up to be heard. A longtime national leader in health, research for health and advocacy, Dr. Herbert Pardes, has been recognized by Research!America in the creation of a new advocacy award that we have just announced. If you know of someone who rises to Dr. Pardes’ level of impact as an advocate, please be sure to nominate that individual to receive recognition next March. See elsewhere in this issue for details.

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

2018 Advocacy Awards
- Takeda
- Vertex

2018 National Health Research Forum
- PCORI

Program Support
- American Society for Microbiology
- Institute of Translational Medicine at the University of Chicago

Program Support (continued)
- Kempe Foundation
- Society for Neuroscience

Visit www.researchamerica.org/partnership_opportunities for ways to support Research!America.

Special Thanks to Renewing Research!America Alliance Members

Renewing Members
- Alzheimer’s Drug Discovery Foundation
- American College of Neuropsychopharmacology
- American College of Surgeons
- American Geriatrics Society
- Americans for Medical Progress
- Association of Medical School Chairs
- Astellas
- Beyond Celiac
- Case Western Reserve University
- Celgene
- EB Research Partnership
- Elsevier
- Friedreich’s Ataxia Research Alliance
- Friends of Cancer Research
- GlaxoSmithKline
- H. Lee Moffitt Cancer Center & Research Institute
- MedStar Health Research Institute
- Medical University of South Carolina
- Morgridge Institute for Research
- Nebraska Coalition for Lifesaving Cures
- Oregon Health & Science University Shire
- Society for Biomaterials
- South Alabama Medical Science Foundation
- Stanford University School of Medicine
- SUNY Downstate
- University of Kansas Medical Center School of Nursing
- University of Tennessee Health Science Center
- Virginia Tech

As of July 11, 2018

An outspoken proponent for academic medicine, children’s health education, mental health issues, access to care and information technology in medicine, Dr. Pardes is a regular guest on national television news programs and contributes opinion pieces appearing in the Wall Street Journal and other newspapers. He is active at the state and federal level, supporting legislation to help hospitals provide quality health care while balancing today’s economic realities with making the best possible medical care available to all who need it.

National Health Research Forum continued from page 1

Dr. Guillermo Prado, dean, Graduate School, Leonard M. Miller professor of public health sciences, director, Division of Prevention Science and Community Health, Miller School of Medicine, University of Miami; Dr. Ivor Benjamin, president, American Heart Association and director of the Cardiovascular Center at The Medical College of Wisconsin; Dr. Gary Cohen, executive vice president of global health, BD; and Dr. Alfiee Breland-Noble, associate professor, Department of Psychiatry, Georgetown University Medical Center.

Panel sponsors include AdvaMed, Amgen, BD, Pfizer Inc and PCORI. For more information and to reserve your space at the Forum, visit www.researchamerica.org/forum.

Federal Policy Update

The appropriations committees in the House and Senate have finished “marking up” their fiscal year 2019 (FY19) spending bills and, when it comes to our nation’s health and science focused agencies, the news has been largely positive. Of particular note, the Senate provided an increase of $2 billion for NIH and, net of transfers and one-time funding, provided a $695 million increase for CDC. The House provided a $296 million increase for FDA as well as a $408 million increase for NSF. Both the House and Senate provided $334 million – the same level as FY18 – to ARHQ, but explicitly rejected calls to roll the agency into NIH.

While both Houses have made significant progress in their respective appropriations efforts, it remains unlikely that the process will be complete by the September 30 end of FY18. We anticipate at least one and potentially several continuing resolutions flat-funding the government before final FY19 budget numbers are signed into law.

As the bills for FY19 were being drafted and sent for mark up, Congress was simultaneously working to address the administration’s rescissions package, which called for impounding and ultimately cutting $15.4 billion in unused discretionary and mandatory spending authority. Two areas of particular concern in the package were cuts of $400 million in USAID Ebola funding and $800 million in Center for Medicare and Medicaid Innovation (CMMI) funding. Although the administration cancelled the proposed Ebola funding rescission, the House passed legislation to implement the other proposed cuts. The Senate, however, voted not to discharge the bill by the June 22 deadline, so no rescissions took place.

The House passed bipartisan legislation giving shape to more than 50 discrete proposals aimed at addressing the opioid crisis, including language intended to amplify efforts to research and develop non-addictive pain treatments.

Another bipartisan bill pending in the House would repeal the medical device excise tax, which has twice been suspended, the second suspension expiring in 2020. While these serial, two-year suspensions are a welcome reprieve from the unintended consequences of this tax on medical technology innovation, a permanent repeal is the only way to alleviate investment uncertainty and fully restore the pace of medical device progress. The most likely path to passage for this legislation is tax extenders or omnibus legislation.

On July 12, Agency for Healthcare Research and Quality (AHRQ) Director Gopal Khanna met with Research!America and Health IT Coalition member organizations to discuss his goals for the agency and vision for a health care system that leverages advances in IT to maximize the societal return on every health care dollar. Mr. Khanna said that to maximize its own return, AHRQ must not only fulfill the continuing demand for health services research, but work closely with other health care stakeholders to anticipate and meet the research needs of a rapidly evolving health care system.
New Foundation Focuses on Public Health Impact of Child Abuse and Neglect

The National Foundation to End Child Abuse and Neglect (EndCAN) aims to change the national conversation on the topic to emphasize the health impact of abuse and neglect. Research!America’s Vice President of Communications Suzanne Ffolios joined the foundation’s co-founders Dr. Richard Krugman and Lori Poland and Colorado Governor John Hickenlooper at the State Capitol on June 18 to launch the foundation and release a national public opinion survey.

Across populations, a strong majority of respondents view child abuse and neglect as a public health problem in the U.S. with 81% of Hispanics, 76% of non-Hispanic whites, 74% of African-Americans and 67% of Asians in agreement. Respondents also say child abuse and neglect is a problem in their local communities and state and federal governments should fund research to better understand, prevent and intervene in child abuse and neglect.

Identifying causes of abusive behavior and treatment to stop it, and best treatments for victims of abuse and neglect should be research priorities, according to survey respondents. “It is not just a social and legal issue, but a major health, mental health and public health problem,” said Governor Hickenlooper. “The approach that EndCAN will bring to this issue is sure to make a difference.”

For more information on the survey, visit http://bit.ly/2L9ydJH.

Panelists Call for Patient-Centered Mental Health Research

Patient voices are crucial to removing the stigma surrounding mental illness and, when included in mental health research, can dramatically improve health outcomes particularly for underserved populations. Health experts discussed opportunities to increase patient involvement in research and barriers to care for mental health patients at a Capitol Hill briefing hosted by Research!America and the Patient-Centered Outcomes Research Institute (PCORI) on Wednesday, June 13. Andrew Sperling, director, legislative and policy advocacy, National Alliance on Mental Illness, moderated the panel.

“Money is an issue, but so is lack of awareness and stigma around mental health,” said Dr. Allee Brelan-Koble, associate professor, Department of Psychiatry, Georgetown University Medical Center. “People who tell their stories [about mental illness] are key to overcoming stigma,” she added.

Marilyn Perez-Aviles, research assistant, Illinois Institute of Technology (IIT), spoke about her experience as a patient navigator in a program run by the Chicago Health Disparities Center and funded by PCORI that pairs mental health patients with those who understand their experiences. The program “really engages the community and helps build trust,” she said. Dr. Patrick Corrigan, distinguished professor of psychology, IIT called for more collaboration with patients in research.

Researchers and health care providers must improve their communication with mental health patients, noted Sonya Ballentine. Dr. Elena Rios, president and CEO, National Hispanic Medical Association, encouraged researchers to develop materials that are more accessible to the public.

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
Vaccines

The American Society for Microbiology and Research!America, in collaboration with the American Society for Virology, held a panel discussion at the Newseum in Washington, D.C. about infectious disease research and public health which aired on C-SPAN. A new public opinion survey about Americans’ views on the safety and effectiveness of vaccines received extensive media coverage in outlets such as NBC News, U.S. News & World Report, and The Hill.

Research!America president and CEO Mary Woolley penned an op-ed published in the Morning Consult urging public health stakeholders to initiate more substantive conversations about the health benefits of vaccines. The Washington Post published a letter-to-the-editor authored by Woolley about public awareness regarding the safety and efficacy of vaccines. The St. Louis Post-Dispatch published a letter-to-the-editor penned by Research!America Vice President of Communications Suzanne Ffolkes about the need for scientists and health professionals to inform the public about vaccines.

Public Health

In an NBC News article about a World Health Assembly resolution promoting breastfeeding over formula, Research!America board member Georges Benjamin, M.D., executive director of the American Public Health Association, commented that the scientific evidence overwhelmingly supports breastfeeding and its health benefits for the mother and child.

Higher Education

Research!America board member Jay A. Gershen, DDS, Ph.D., president, Northeast Ohio Medical University (NEOMED), and Bruce Johnson, president of the Inter-University Council of Ohio, co-authored an op-ed published in The Cleveland Plain Dealer about the importance of maintaining a high-quality public higher education system to address workforce challenges and spur economic growth in the state.

Children’s Health

Research!America board member James Madara, M.D., EVP and CEO, American Medical Association, sent a letter to the Trump Administration about the health impact of children separated from their parents at the U.S.-Mexico border which was featured in a CNN article.

Pharmacists as Patient Partners

In a Hill op-ed, Research!America board member, Lucinda Maine, Ph.D., R.Ph., executive vice president and CEO, American Association of Colleges of Pharmacy (AACP), wrote that pharmacists can help manage drug costs if state and federal laws would allow.

IN BRIEF

- Research!America board members Dr. James Madara and Dr. Harold Paz were named in Modern Healthcare’s “50 Most Influential Physician Executives and Leaders 2018.”
- BIO released the “Value of Bioscience Innovation in Growing Jobs and Improving Quality of Life 2018” report with TEConomy Partners.
- FasterCures will be hosting a webinar “The Game-Changing Impact of Empowering Patients with Health Data” on July 19.
- The Diabetes Emergency Relief Coalition, led by the American Diabetes Association, received the American Society of Association Executives (ASAE) 2018 Summit Power of A Award.
  http://bit.ly/2L9c52g
Communication Key to Tackling Disease Outbreaks

Vaccines and stronger public health infrastructures are critical to tackle global health threats, said experts at a briefing hosted by Research!America and the American Society for Microbiology (ASM) at the Newseum in Washington, D.C. on May 21.

The program coincided with the opening of the Smithsonian’s “Outbreak” exhibit and the release of a public opinion survey that found 95% of Americans think infectious and emerging diseases facing other countries will pose a ‘major’ or ‘minor’ threat to the U.S. in the next few years. “It’s not a question of if there will be another outbreak but when,” said Dr. Stacey Schultz-Cherry, president, American Society for Virology.

“It’s important for those who work with, and who oversee the government, to educate, surveil, and detect infectious diseases and communicate with the public what they need to know,” said Mary Woolley, president and CEO, Research!America.

Dr. Anthony Fauci, director, National Institute of Allergy and Infectious Diseases said a universal flu vaccine would safeguard against many strains of flu, including those that cause pandemics. Dr. Nancy Messonnier, director, National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, called immunization a public health success story. “Even for diseases for which we have less than perfect control, like pertussis, mumps and measles, we’re still preventing 90% of the cases that occurred a century ago,” she added. Watch a recording of the event at https://cs.pn/2rzXVwR.

Innovation and Patient Access to Treatments

Research!America president and CEO Mary Woolley moderated a panel discussion on a timely and challenging topic, “Breakthrough Medicine: How Can Patients Afford it?” at the Aspen Spotlight Health Conference on June 22 in Aspen, Colorado. She opened the session by citing public opinion survey data showing deep public unhappiness about high costs and lack of access, as well as declining trust.

Gary Reedy, CEO, American Cancer Society, emphasized that all stakeholders—very much including patients - must be involved in discussions of affordability and innovation. Referencing the importance of access he said, “Where you live should not determine if you live.” Andy Slavitt, founder and chairman, United States of Care, observed that it is a ‘false choice’ to not have both innovation and affordability. It’s all about constant drive for value.

Woolley challenged the panelists to go beyond oft-cited calls for ‘systemic change’ to be specific about how to increase value. Panelist Jeff Marruzzo, CEO of Spark Therapeutics, which has made news recently with a one-time intervention to reverse blindness, said his company has launched patient-friendly initiatives such as alternative payment models and outcome-based rebates. Other potential solutions include negotiated discounts at the pharmacy, improving options for seniors in Medicare Part D, and re-evaluating the reimbursement system, suggested Steve Ubl, president and CEO of PhRMA.

Building Public Trust in Science and Scientists

Trust and collaboration between the general public and the scientific community is vital to maintaining our nation’s global leadership in science and technology. Yet, there is a disconnect between the public and scientists in terms of understanding the societal impact of science, according to a panel of experts at the BIO International Convention in Boston, Massachusetts held on June 6. Seema Kumar, vice president of innovation, global health and policy communication, Johnson & Johnson, moderated the panel.

Our nation’s “science enterprise is at risk if the science community remains essentially invisible to the general public,” said Research!America president and CEO Mary Woolley. “To reinforce trust, and build relationships, communication between the science community and the public must improve,” she added. “It’s up to scientists to be more accountable, to reach out to say, ‘I work for you’ to the public that is paying the bills via their tax, consumer and philanthropic dollars.” The connection between good health and scientific research must also be made clear to the public, said Dr. Bill Hait, global head, Johnson & Johnson External Innovation.

Dr. James Allison, chair of the Department of Immunology at the University of Texas MD Anderson Cancer Center and recipient of the Dr. Paul Janssen Award, said awards help to increase public awareness of the achievements of scientists and scientific progress. Lucia Brown, the 2018 BioGENEius Hall of Fame Recipient, said a lack of diversity in science could also be a factor in public distrust. “When you have individuals who do not look like you at the head of the table, how can you then trust that the research that is being done is actually for you?” Ashanthi De Silva, a rare disease blogger and patient advocate, said the National Institutes of Health’s All of Us Initiative which is gathering data from individuals across different backgrounds to accelerate research could help address the diversity issue.
Boston Children’s Hospital (BCH) invests heavily in research because science saves lives. They are focused on accelerating new treatments for devastating diseases as our discoveries translate from the laboratory bench to the patient’s bedside, where they have been improving the health of children and adults since 1869.

The research enterprise at Boston Children’s Hospital (BCH)—comprising more than 3,000 researchers and representing annual expenditures of greater than $375 million—is the world’s largest at a pediatric center. Their work is fueled by a deep understanding of disease coupled with world-class discovery platforms, including genetics and genomics, gene editing, bioinformatics, proteomics, bioengineering, image analysis, multiple animal models, biobanks and disease-specific stem cell lines. The hospital has special expertise in rare disease discovery and see large, highly diverse patient populations.

“Members of our research community include nine members of the National Academy of Sciences, 18 members of the National Academy of Medicine, 16 Howard Hughes Medical Institute Investigators and alumni, and eight Lasker Award recipients,” said August Cervini, Vice President, Research Administration at BCH. “In total, our research community publishes more peer-reviewed research in top scientific journals than the next 20 children’s hospitals combined — more than 3,000 annually.”

One of the most exciting endeavors in science at Boston Children’s Hospital is around stem cell research. Stem cell clinical trials underway at Boston Children’s include a trial that will be among the first to differentiate stem cells into tissues and transplant them into diseased organs. In another trial, a patient has already been treated with retinal cells for macular degeneration of the eye, derived from induced pluripotent stem cells.

A separate trial hopes to turn pluripotent cells into natural killer cells that could be used to fight tumors. “Overall the hope at BCH is to have the ability to transfuse stem-cell-derived platelets into patients who cannot receive normal platelet units because they develop antibodies against them,” explained Mr. Cervini.

BCH’s investigators—as well as researcher across the country—are on the precipice of discovering new therapies for deadly diseases and continuous support of medical research will benefit Americans for generations to come. Their national investment in research is also a key economic driver at the local, state, and federal level as we closely watch how other nations—especially China—are increasing their commitment to research.

“Boston Children’s relationship with Research!America is critically important to educating Congress about how essential it is to invest in the nation’s burgeoning biomedical science environment,” said Mr. Cervini.

“Since its founding in the late 80s, Research!America has played an incredible important role in mobilizing and leveraging the funding, advocacy and input of the federal government, academia, industry and philanthropy to meet our national goal of improving human health,” he added. Boston Children’s Hospital is proud to be listed as a contributing member of one of our nation’s most effective advocacy organizations.

For more information, visit www.childrenshospital.org.
In order to enhance our understanding of disease and discover life-saving breakthroughs, the National Institutes of Health (NIH) relies on the support of Congress. Encourage your elected officials to take a leadership role in the Senate and House NIH Caucuses.

The NIH Caucus plays an essential role in ensuring that robustly funding the NIH is assigned a top priority. In creating a concrete strategy to increase federal funding for the NIH, the Caucus allows the United States to remain a world leader in science and health care innovation. Through the life-saving research NIH supports, our nation can defeat illnesses that rob Americans of health, hope, and time.