March for Science Garners Widespread Support Across U.S. and Abroad

Hundreds of thousands of scientists and science enthusiasts of all ages and backgrounds participated in the March for Science on April 22 in more than 600 cities worldwide. As a partner in the global grassroots movement, Research!America staff participated in marches in Washington, D.C., Los Angeles, CA, Oklahoma City, OK, and Salt Lake City, UT. A video featuring Research!America president and CEO Mary Woolley and science policy fellow Anna Hatch, Ph.D., was shown during the event. “Science is a field of dream for all of us…everyone who cares about the future of health and economic prosperity in this country must speak up now,” said Woolley in the video.

Among the Washington, D.C., March for Science speakers were Research!America board members Rush Holt, Ph.D., CEO of the American Association for the Advancement of Science and Georges Benjamin, M.D., director of the American Public Health Association. Dr. Holt spoke about the public policies that are essential for achieving scientific progress, “Science needs certain conditions to thrive: free exchange of ideas, freedom to travel and collaborate, diversity of people and perspectives and ample public funding. These conditions are threatened today and we must defend them.” Dr. Benjamin underscored the value of a strong public health infrastructure in his remarks, “Public health science is the heart of so many successes that have prolonged our lives and improved our well-being…a strong commitment to research is absolutely essential to draft the evidence-based solutions that protect us from serious health threats.”

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BIO Convention Session on Achieving a World Without Disease

Research!America is hosting an interactive panel discussion, A World Without Disease: Can We Get There?, on June 20 at the BIO International Convention in San Diego, California. Panelists include Mark McClellan, M.D., Ph.D., M.P.A., director, Duke-Robert J. Margolis, MD, Center for Health Policy, Duke University and Research!America board member; William Hait, M.D., Ph.D., global head at Janssen Research and Development and Research!America board member; and Donna Cryer, JD, president and CEO of the Global Liver Institute. Luke Timmerman, founder and editor, will moderate the panel.

The discussion will explore the current biomedical landscape, from implications of new technologies and challenges of leveraging limited resources to maximize patient benefit, to the scope and pace of medical progress. Panelists will address questions such as: How is success defined? and What are the true limits to extending the healthy lifespan and eradicating disease?

continued on page 3

Plurality Willing to Pay More in Taxes to Address Health Threats

Would you be willing to pay $1 per week more in taxes to support an emergency public health fund to address health threats like Ebola?

continued on page 3
PRESIDENT’S LETTER

It’s a fact! Advocacy works. Against what many described as long odds, the recently enacted FY17 appropriations legislation notably includes a $2B increase to the NIH. Other health science agencies fared reasonably well, under trying circumstances, including OMB recommendations for severe cuts. Still, we note with chagrin that CDC and AHRQ received cuts. We have a long way to go, as stakeholders in our collective future, and as a nation aspiring to better health, security and economic prosperity, to connect all the dots and invest accordingly. In the immediate, the path forward demands attention to the FY18 appropriations process, already underway albeit absent clear directional signals from the new Administration and influenced by an abundance of unresolved issues, not least, the angst-ridden day to day status of health care ‘reform’ legislation that was approved in the House and sent to the Senate.

To me, the bottom line is that we cannot afford to acquiesce in a ‘think small’ mentality. Our goal cannot be about defending the so-called status quo from real or feared attack; rather it must be to commit to continuing to make progress in assuring we achieve personal and societal aspirations for doing better and better – for achieving what is possible if we fully power science and innovation to address what ails us, and not ever settling for less. Keeping a steady course toward our goals is imperative. Also imperative is expression of your passion for the cause. Thank you for your commitment and for your partnership.

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

2017 Advocacy Awards
Alnylam Pharmaceuticals
amfAR, The Foundation for AIDS Research
Faegre Baker Daniels Consulting
The Johns Hopkins University
Takeda Pharmaceuticals U.S.A., Inc.

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

Special Thanks to Renewing Research!America Alliance Members

**Renewing Members**
- The ALS Association
- American Psychiatric Association
- American Society of Gene & Cell Therapy
- Association for Women in Science
- Case Western Reserve University
- Cold Spring Harbor Laboratory
debra of America
- Feinberg School of Medicine, Northwestern University
- Gates Center for Regenerative Medicine
- GlaxoSmithKline
- Greater Akron Chamber
- Harvard School of Dental Medicine
- Howard Hughes Medical Institute
- Kent State University
- Kidney Cancer Association
- National Foundation for Infectious Diseases

- South Alabama Medical Science Foundation
- Stanford University
- School of Medicine
- University of California, San Diego
- School of Medicine/ Health Sciences
- University of Pittsburgh
- School of Nursing
- University of Southern California
- School of Social Work
- Youngstown/Warren Regional Chamber

March for Science continued from page 1

“Our numbers here today show the world that science is for all. Our lawmakers must know and accept that science serves everyone of us, every citizen of every nation and society,” said Bill Nye, the Science Guy, guest speaker at the march in Washington, D.C., and honorary co-chair. “Science must shape policy, science is universal, science brings out the best in us. With an informed optimistic view of the future together…[we can…dare I say it] can save the world.”

Research!America march for science branded buttons were distributed at the Washington, D.C., and satellite marches and messages from the day were captured across social media channels. On-the-ground highlights from Research!America staff at satellite marches are available at: http://bit.ly/2pEA4hG.

BIO Convention continued from page 2

The panelists’ broad and unique experiences, from federal, industry, academia and patient perspectives, will allow for a dynamic discussion on a variety of topics impacting the biomedical community and its future.

The BIO International Convention is the largest global event for the biotechnology industry and attracts the biggest names in biotech, offers key networking and partnering opportunities, and provides insights on major trends affecting the industry. This event covers a variety of research areas, including drug discovery, biomanufacturing, genomics, biofuels, nanotechnology and cell therapy. In addition to the wide variety of sessions, the convention will also have an Exhibition Hall, where many of Research!America’s alliance members will be exhibiting. For more information visit www.convention.bio.org.

Federal Policy Update

President Trump is expected to sign an FY17 omnibus appropriations bill by May 5 that provides $1.7 billion in new budget authority for NIH and reaffirms the availability of an additional $300 million in targeted 21st Century Cures funds for NIH. CDC will receive a cut of about $13 million; FDA will receive an increase of $30 million; NSF will receive an increase of $10 million; and AHRQ will receive a cut of $10 million.

Next, members of Congress will turn their attention to FY18 appropriations. Unless there is another deal to increase discretionary spending beyond the level allowed by the “sequestration” budget caps (the last deal covered FY16 and FY17 only), the caps on non-defense discretionary spending (NDD) will be $3 billion lower in FY18 than in FY17.

The President has not yet sent a detailed budget proposal to Congress, but his “skinny budget” specified a $5.8 billion cut in NIH, accomplished via cuts to indirect costs, the elimination of the Fogarty International Center, and other consolidation/reorganization of the Institutes and Centers. The President’s skinny budget also proposed the consolidation of AHRQ into NIH. It is unclear how Congress will respond to these proposed changes or the funding levels assumed in the President’s budget (the caps were modified to permit an additional $54 billion in defense spending and a corresponding reduction in non-defense spending).

On Thursday, May 4, the House voted to repeal the Affordable Care Act and replace it with legislation that, among its fundamental changes, would eliminate the Prevention and Public Health Fund (PPHF) and repeal the medical device excise tax. The Senate has not indicated when it might take up the bill, which is not expected to pass that body in its current form.

In regulatory news, the Senate HELP Committee voted to confirm Dr. Scott Gottlieb for the role of FDA Commissioner. The full Senate has not yet considered Dr. Gottlieb’s nomination, but it is expected that he will be confirmed.

On April 13, we held a well-attended Alliance Member meeting/call with federal budget expert, David Reich. We have issued several new and updated advocacy materials, including new fact sheets providing a snapshot of medical and health research on a state-by-state basis, updated fact sheets on pain, multiple sclerosis (MS), and osteoporosis & hip fractures, and a new fact sheet on opioid and other substance use disorders. For fact sheets, visit http://bit.ly/2dT9D0w.
**In Memory of Trish Vradenburg**

Trish and George Vradenburg at Research!America’s 2016 Advocacy Awards Dinner.

UsAgainstAlzheimer’s co-founder and vice-chair Trish Vradenburg, a gifted and powerful advocate, passed away on Monday, April 17. Founded with her husband George Vradenburg, UsAgainstAlzheimer’s is committed to finding a cure for Alzheimer’s by 2025. Their advocacy was born out of a passion to fight back against Alzheimer’s disease, which Trish’s mother, Bea Lerner, succumbed to in 1992.

Mrs. Vradenburg helped achieve increased funding for Alzheimer’s research and spearheaded the launch of the Alzheimer’s Party, imploring members of Congress to join a bipartisan movement to end Alzheimer’s disease.

The Vradenburgs received Research!America’s Gordon and Llura Gund Leadership Award in 2016 for their outstanding commitment to advocacy.

Mrs. Vradenburg began her career as a speechwriter in the U.S. Senate. She wrote for various television shows, including Designing Women, Family Ties and Kate and Allie. Her novel, Liberated Lady, was chosen as Literary Guild and Doubleday Book Club selections.


**Removing Barriers to Clinical Trial Participation**

Lack of awareness of clinical trials is among key factors contributing to low participation rates throughout the country, according to a panel of experts at a Capitol Hill briefing in Washington, D.C. hosted by the Coalition for Clinical Trials Awareness on May 3. David Charles, M.D., chair of The Alliance for Patient Access, said more people would enroll if they knew about trials, adding that a sustained national public awareness campaign supported by the public and private sector might fill knowledge gaps. He suggested the creation of a task force of key stakeholders that would make recommendations on ways to elevate awareness.

Data quality improvements, transparency and diversity in trials are among the priorities for the Food and Drug Administration (FDA) in efforts to boost enrollment, said Jonca Bull, M.D., assistant commissioner for minority health, Office of the FDA Commissioner. “Patients in trials should reflect the patients who receive these new drugs,” she said, noting that access to trials is a barrier for many segments of the population. “We must bring the trials to patients and span the pool of investigators,” she said.

The panel agreed that altruism is a motivating factor for clinical trial participation. Sara Chang, director of policy and advocacy, Research!America, said survey results show a majority of Americans say improving the health of others would be an important consideration in deciding whether to enroll in a trial. She added that many respondents are also willing to share their personal health data to advance medical research, in surveys commissioned by Research!America.

Renata Louwers, a former caregiver whose husband died of metastatic bladder cancer, said there’s a “shortage of help for people trying to find a trial.” She suggested that patients should have someone available to “guide them through the process.” Guest speaker Representative Diana DeGette (D-CO-01) said she introduced bipartisan legislation that would provide support to clinical trial patients with psychological and social distress.

**Hill Briefings on Clinical Research and Migraine**

Research!America is hosting a congressional briefing, Innovation Intersection, Monday, June 12 in the Capitol Visitors Center, noon to 1 p.m., and another briefing, The Value of Research and Prevention in Addressing the Societal Burden of Migraine, Thursday, June 15 in the Rayburn House Office Building, Room 2043, noon to 1 p.m. Experts from across the research and public health continuum will participate in the panel discussions, focusing on the development phase of the discovery, development and delivery pipeline, clinical research and potential solutions to the burden of migraines on society.

Speakers for the Innovation briefing include John Hubbard, Ph.D., FCP, chairman, Association of Clinical Research Organizations (ACRO), president and CEO, Bioclinica; Victor J. Dzau, M.D., president, National Academy of Medicine and Research!America board member; Patty Fritz, M.S., vice president of U.S. corporate affairs, UCB Inc; and Sudip S. Parikh, Ph.D., senior vice president and managing director, DIA and Research!America board member. The discussion will be moderated by Eleanor M. Perfetto, Ph.D., M.S., senior vice president of strategic initiatives, National Health Council.

The Migraine briefing will feature Walter Koroshetz, M.D., director, National Institute of Neurological Disorders (NINDS); Mary Franklin, executive director, National Headache Foundation; Brian Gifford, Ph.D., director, research and measurement, Integrated Benefits Institute; Jaime Sanders, The Migraine Diva, migraine patient advocate; and Amaal J. Starling, M.D., assistant professor of neurology, Mayo Clinic. For more information and to RSVP, visit http://bit.ly/2q39WYf.

**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
FY17 Budget

Research!America president and CEO Mary Woolley was quoted in The Atlantic, Diverse Issues in Higher Education and Bloomberg BNA regarding the $2 billion increase for NIH in the FY17 omnibus bill.

Research!America VP of Communications Suzanne Ffolkes was quoted in Diverse Issues in Higher Education about the importance of sustained, predictable funding increases for NIH.

Improving Children’s Health

In a New York Times article, Nancy Brown, CEO of the American Heart Association and Research!America board member, discussed limiting sodium and sugar levels in school lunches to lower high blood pressure, heart disease and stroke risk in children.

March for Science

Research!America’s 2017 national public opinion survey was included in a Washington Post article about the March for Science.

Research!America board member Rush Holt, Ph.D., CEO of the American Association for the Advancement of Science, was quoted in Chemical & Engineering News, R&D Magazine, The Washington Post, and other publications about the role of scientists in policymaking following the March for Science.

Woolley appeared in the Genetic Engineering & Biotechnology News podcast to discuss the March for Science and the importance of funding for federal research agencies.

Research!America board member Georges Benjamin, M.D., executive director of the American Public Health Association, was quoted in Medscape and ThinkProgress articles about the March for Science and the role of science in public health.

DrugTopics magazine featured Research!America board member Lucinda Maine, Ph.D., R.Ph., executive vice president and CEO of the American Association of Colleges of Pharmacy (AACP), in an article about AACP’s March for Science participation.


Ffolkes wrote letters to the editor in The Daily Sentinel (Grand Junction, Colorado) and the Hartford Courant, urging scientists to speak up and participate in the March for Science.

Woolley wrote a Miami Herald op-ed about the need to boost research funding and the significance of the March for Science.

Cancer Research Funding

The Chicago Tribune highlighted the 2017 Discovery Ball which raised $6 million to fund cancer research and highlighted remarks from Research!America board member Gary Reedy, CEO of the American Cancer Society.

IN BRIEF

• The Innovation: An American Imperative report urges Congress to enact policies and make investments to ensure the U.S. remains a global leader in innovation.

• Research!America board member Susan Dentzer, CEO, Network for Excellence in Health Innovation, will lead a day-long meeting, “Health Care Without Walls,” on May 10, 2017.
  http://bit.ly/2pCQJS1

• The American Association of Colleges of Nursing, along with Research!America, will shine a spotlight on nurse researchers during 2017’s National Nurses Week, May 6-12.
  http://bit.ly/2qJ0hJt

• The Clinical Research Forum held the Top Ten Clinical Research Achievement Awards Ceremony on April 18, 2017 in Washington, D.C.
Putting a Face on Scientific Research

Medical and health research is conducted in all 50 states yet only one in four Americans know that, and two-thirds cannot name a place where research is conducted, according to survey findings shared by Research!America president and CEO Mary Woolley that surprised young researchers at the National Institutes of Health (NIH). During a presentation at NIH on May 3, Woolley shared tips on how to be an advocate for research to spread the word about the value of science.

“We know the public is positive about science and wants scientists to engage,” she said. “Start by telling your family and friends about NIH research and where it’s conducted nationwide. Say and convey, ‘I work for you; your tax dollars support me and scientists around the nation.’”

It’s also important, she said, to reach out to policymakers. “We are told by members of Congress that no one in their district, including scientists, have ever approached them about the importance of supporting NIH,” Woolley said. “Elected officials and scientists both serve the public so start a conversation based on that. Thank them for their service and don’t be confrontational.”

She also reminded attendees that advocacy is about more than being vigilant; it’s about being proactive. “The point is to get over that invisibility and put a face on research -- yours!”

Too Sick to Take it Lying Down: Patients with ME/CFS will Converge on Washington, D.C.

The Solve ME/CFS Initiative and #MEAction will be hosting a congressional briefing on May 18, The Invisible Health Crisis: ME/CFS, to discuss the disease and the desperate need for federal funding for research. Panelists will include Jennifer Brea, award-winning filmmaker, TED fellow and co-founder of #MEAction; Carol Head, MBA, president and CEO of the Solve ME/CFS Initiative; and Zaher Nahle, Ph.D., chief scientific officer and VP of research of the Solve ME/CFS Initiative.

Despite an estimated 2.5 million Americans who suffer with this devastating, chronic illness, ME/CFS remains in the bottom 4% of diseases funded by government research. ME/CFS leaves up to 89% of patients disabled, costing the U.S. economy between $17-24 billion annually. At this time, there is no FDA-approved treatment and no cure.

As part of a national campaign, 55 patients and their loved ones will travel from 24 states, territories, and districts to visit Capitol Hill during ME/CFS Awareness week in May to meet with congressional staff. These advocates will join with thousands of others, too sick to travel, participating in the effort online and by phone.

To learn more and attend an awareness event near you, visit http://bit.ly/2PpmokY.

Communicating Academic Research to a Broader Audience

Colorado State University (CSU) researchers and faculty shared their perspectives on science advocacy and public engagement with Research!America Vice President of Communications Suzanne Ffolkes at the Women in Science Workshop, hosted by CSU, and Science on Tap, a program that connects science with the Fort Collins community.

With growing uncertainty about sustained public investments in academic research, attendees at both events, held April 12-13, expressed interest in boosting their engagement with policymakers and the public to ensure the health and economic benefits of research are being communicated to a broader audience. Ffolkes, a presenter at the workshop and Science on Tap, said building relationships and thanking policymakers for their support are necessary to help elevate scientific research as a national priority. A majority of Americans across the political spectrum agree that public policies should be based on the best available science, she added. Ffolkes urged researchers to keep abreast of policy developments related to research on the state and federal level, and seek opportunities to promote academic research supported by public investments with decision-makers and the public to increase awareness.
The American Association of Tissue Banks (AATB) is a professional, non-profit, scientific and educational organization. The AATB accredits facilities for the handling of a variety of donated human tissues including autologous, birth, cardiac, cellular, musculoskeletal, vascular, reproductive, skin, surgical bone, and non-transplant anatomical material. In addition, the AATB accredits tissue banking facilities for activities including acquisition, collection, distribution, intermediary, preparation, processing, recovery and storage of human tissue. Membership includes more than 130 accredited tissue banks and 2,000 individual members.

The AATB’s Scientific and Technical Affairs Committee rewards new scientific research every year through the competitive and prestigious AATB Abstract Awards Program. Tissue banking professionals from around the world submit research for peer review.

The AATB has a history of supporting research - AATB founding father, Dr. Kenneth Sell served as scientific director of the National Institute of Allergy and Infectious Diseases in the early 1980s. Sell was among the first to recognize the early threat of AIDS and he quickly allocated researchers and resources to fight this disease. He started a program to gather blood and other bodily fluid samples from HIV+ patients in order to store them for research.

First published in 1984 and presently in its 14th edition, the AATB’s Standards for Tissue Banking are recognized around the world as the definitive guide for tissue banking. These Standards are the only private tissue-banking standards published in the United States, and they are the most comprehensive and detailed tissue-banking standards in the world. As such, the AATB’s Standards have served as the model for federal and state regulations as well as several international directives and standards. Currently, the statutes and/or regulations of more than 20 states reference AATB’s Standards, institutional accreditation, or individual certification. At least six states require AATB accreditation for any tissue bank operating in their state.

Beginning in 1986, the AATB initiated a mandatory Accreditation Program for its institutional members to ensure that tissue-banking activities are performed in a professional manner in compliance with its Standards. Today, the AATB Accreditation Program remains the only private accreditation program for tissue banks in the U.S. In 1988, the Association also began a Certified Tissue Banking Specialist (CTBS) certification program for individuals working in tissue banking. Today, nearly 4,000 individuals have been awarded the CTBS certification.

“Thanks to the work of professionals in the tissue banking field, donated human tissue has an outstanding record of safety in the United States,” stated AATB president and CEO, Frank S. Wilton. “As modern medicine advances, so will the critical role of the AATB.”

One of the most beneficial aspects of AATB’s Research!America membership is the abundance of opportunities to collaborate with other Research!America members including universities, independent research institutes, academic health centers, industry stakeholders, scientific societies and patient advocacy organizations in our common goals.

AATB is proud to be a member of Research!America and support their efforts to increase support for research into prevention, treatments and cures.

For more information, visit www.aatb.org.
Senator Bob Casey (D-PA) and Senator Richard Burr (R-NC) have penned a "Dear Colleague" letter to Senate Appropriators requesting robust funding for the National Institutes of Health (NIH) in FY18. Ask your Senators to add their name to the letter by sending them a message.


Deadline to submit nominations for Research!America's 2018 Advocacy Awards is May 19, 2017: www.researchamerica.org/nominations