Public and private partnerships and stronger investments in research could help patients living with chronic obstructive pulmonary disease (COPD). Experts representing the COPD research continuum discussed the latest developments in research and the prevention and treatment of the disease at a congressional briefing hosted by Research!America titled “From Discovery to Delivery: Research at Work – COPD” on November 15, 2017. Lisa Simpson, MB, BCH, MPH, FAAP, president and CEO, AcademyHealth, moderated the panel.

Nearly 16 million Americans live with COPD, an umbrella term used to describe progressive lung diseases. COPD is the third leading cause of death in the U.S., claiming the lives of 150,000 each year said Grace Anne Dorney Koppel, JD, M.A., president, Dorney-Koppel Foundation.

Koppel, a COPD patient and advocate, pleaded for increased federal funding for research to expand treatment options for patients. She noted that current treatments do not stop the progression of the disease. “Not being able to breathe, the most essential quality of life, is terrifying,” she said.

David Mannino, M.D., FCCP, FERS, U.S. respiratory medical expert, added that some advances have been made in COPD research “but we still have a long way to go.”

Gary Gibbons, M.D., director, National Heart, Lung, and Blood Institute (NHLBI), discussed the COPD National Action Plan that was released by the Institute earlier this year. The plan provides a comprehensive framework for patients and disease stakeholders who are committed to reducing the burden of the disease. “We’re all in this together and we’re on the same team,” he added.

Effectively Communicating Public Support for Science

Public support for science can have a profound effect on policymaker support for research funding. Effectively communicating about the importance of science, the patient experience and recent discoveries that have potential policy implications is integral to connecting with both the public and policymakers.

To delve further into public sentiment, Research!America and the Society for Neuroscience hosted a webinar, “Leveraging Public Opinion in Support of Science” on Monday, December 4. The webinar was moderated by Anna Briseno, senior manager of communications, Research!America.

National public opinion survey data commissioned by Research!America shows that while public support for science is strong, few Americans understand our nation’s scientific enterprise. Only 19% of Americans can name a living scientist, and 33% of Americans can name an institution, company or organization where medical or health research is conducted.

“This invisibility problem is concerning for the science community, but it is amenable to change through meeting members of the non-science trained public more than halfway, including policymakers.” said Mary Woolley, president and CEO, Research!America. “Being an advocate, connecting to people, is about engaging hearts and minds, and making engagement in public outreach the new normal for the science community.”
As we go to press, the Administration and Congress are in deep negotiations on several key matters, including funding the government and tax reform legislation that will affect all Americans for years to come. A number of polls reported in the media show that health concerns – including coverage and cost – rank above jobs and defense as public priorities. That reality is one of the key drivers behind the advocacy we pursue on an hourly basis (things are changing that fast right now). By definition, policymakers have many demands on their attention. I urge you to join us in assuring they don’t overlook the future of our nation’s health. Investing in the people – including STEM students from K-12 through post-docs – who will provide the brainpower for a globally competitive and health-enhancing future for the nation, is absolutely essential. So are policies that stimulate instead of hold back innovation in all sectors. As a tumultuous year draws to a close, please join me and all of us at Research!America in encouraging the people we have elected to office to take steps this month to make 2018 a year of extraordinary accomplishment in science as we find solutions to what ails us.
COPD Briefing continued from page 1

Public and private sector investments have been critical to advancing COPD research, said Jerry Krishnan, M.D., Ph.D., associate vice chancellor for population health sciences, professor of medicine and public health, University of Illinois at Chicago. He also underscored the value of comparative effectiveness research to ensure patients receive the best treatment available. “[CER] gives us the tools and knowledge so we are not guessing…what each individual patient needs.”

Communication Webinar continued from page 1

Christopher Volpe, Ph.D., executive director, ScienceCounts, described that organization’s aim to understand what’s going on in the hearts and minds of people when they think of science. Through ScienceCounts’ national benchmark segmentation survey conducted in collaboration with Research!America, certain aspirational terms were identified that resonated most with the public, such as “discovery,” “invention” and “technology,” and most of all, “hope.” ScienceCounts is currently wrapping up a pilot program in stimulating action in support of science.

Navneet Matharu, Ph.D., postdoctoral fellow, University of California San Francisco, discussed the implementation of the 3-Minute Thesis model of communication, and provided tips on communicating scientific research effectively and concisely. Dr. Matharu emphasized that it’s important to include a metaphor, narrative or story that connects emotionally with the audience. Research!America and the Society for Neuroscience will host three more webinars in 2018, learn more and register here: http://bit.ly/2zYd6oe.

Hurdles Still to Overcome for FY18 Appropriations

On December 7, Congress passed another short-term continuing resolution (CR) to avert a government shut-down. Reportedly, Congressional leaders hope that this two-week CR will give them enough time to secure a two-year budget deal that lifts the FY18 and FY19 “sequestration” spending caps.

It is unlikely that during this brief and jam-packed time period they can also pass a final FY18 appropriations package based on the new caps, so another CR that delays final action until January or February of next year is anticipated. Since continuing resolutions tend to leave federal agencies in a holding pattern at best, the sooner a budget deal is reached and FY18 appropriations are completed, the better.

Regarding the budget deal, congressional leaders are reportedly considering cap increases for FY18 and again in FY19 in the range of $54 billion to $63 billion for Defense and $37 billion to $52 billion for non-Defense (NDD) spending. Research!America spearheaded a joint advocacy/advertising campaign making the case for reaching a budget deal as soon as possible this year that results in increased funding for our nation’s science agencies, and are encouraging the use of our #RaiseTheCaps advocacy tools to keep the pressure on until a deal is signed into law.

The House and Senate have passed their respective tax reform packages and are currently attempting to reconcile the two bills into a final bill. On November 16, Research!America held a special Alliance Member meeting/call with Holland & Knight tax experts Robert Bradner, Kathleen Nilles and Nicole Elliott about the impacts – good and bad – of pending tax reform. As conference negotiations continue, Research!America is working to prevent inclusion of provisions that would reduce access to higher education and eliminate the orphan drug tax credit.

On November 28, Morning Consult published an opinion piece Research!America Vice President of Policy and Advocacy Ellie Dehoney wrote advocating for repeal of the medical device excise tax. We have also sent letters to House and Senate leadership calling for repeal of the tax. At this point, the most likely path forward is another two-year suspension of the tax as part of a bill to extend expiring Medicare programs.
Neuroscientists Learn How to Navigate Basic Research Advocacy

Naomi Charalambakis, Ph.D. candidate at the University of Louisville, struggled with an eating disorder as a young adult which compelled her to learn more about how the brain works and eventually become a research advocate. The importance of advocating for robust federal investments in basic science to help understand eating disorders, mental health issues and other diseases was the focus of a panel discussion at Neuroscience 2017 in Washington, D.C. on November 14, 2017.

“As scientists, your voice is very, very important,” said Andrew Sperling, director of legislative advocacy for the National Alliance on Mental Illness, when referring to the influence scientists have on policymakers and their staff as they are making research funding decisions. Lack of funding for mental illness has led to fewer treatments available for patients with disabling conditions, such as schizophrenia, he said.

Mary Woolley, Research!America president and CEO, shared public opinion survey data which showed that Americans believe scientists should play a major role in shaping public policy. The data also revealed that scientists and research institutions in the U.S. are largely invisible in society. Woolley emphasized the need for scientists to engage not only with policymakers but with other non-scientific audiences to drum up support for research. “You cannot outsource advocacy,” she added.

#RaisetheCaps Joint Ad Campaign

Research!America led a multi-faceted ad, digital and grassroots campaign the week of November 13-17 to urge Congress to raise budget caps in FY18 and provide flexibility to increase federal funding for science. Several scientific organizations joined the initiative which included full page print ads in The Wall Street Journal, POLITICO, Washington Examiner and The Weekly Standard, and digital ads in The Hill, Q2 Roll Call, washingtonexaminer.com, weeklystandard.com and DailyCaller.com.

The Bipartisan Budget Act of 2015 provided relief from sequestration -- automatic spending cuts -- for two years, but the budget caps are now back in full force, jeopardizing scientific research and innovation. The campaign urged Congress to negotiate a deal to raise the budget caps for FY18 and FY19 for both R&D and non-defense discretionary spending.

Campaign partners included the American Association for the Advancement of Science, American Educational Research Association, American Geophysical Union, American Physical Society, Federation of American Societies for Experimental Biology, March for Science, National Association for Biomedical Research, OSA-The Optical Society, Society for Neuroscience, and Supporters of Agricultural Research Foundation. Learn more at www.researchamerica.org/raisethecaps.
Raise the Caps

Research!America President and CEO, Mary Woolley, penned an op-ed for The Huffington Post about the urgent need for Congress to negotiate a budget deal to raise the federal spending caps to support science and innovation. “Members of Congress must recommit to driving scientific progress, a national imperative that is too easily taken for granted,” she wrote.

The St. Louis Post-Dispatch published a letter-to-the-editor written by Research!America Vice President of Communications Suzanne Ffolkes about the importance of raising budget caps. “Federal spending caps are limiting opportunities for scientists to launch and sustain research aimed at combating cancer, Alzheimer’s disease and many other health threats.”

Opioid Crisis

In a U.S. News and World Report article about the increase in drug overdoses in West Virginia, Research!America board member Georges Benjamin, M.D., executive director, American Public Health Association, commented on the complexity of implementing policies to curb opioid-related deaths in the state and across the country.

R&D Investments

U.S. Investments in Medical and Health Research and Development 2013-2016, a comprehensive R&D report from Research!America highlighting investments in medical and health research was the focus of articles in Becker’s Hospital Review, Healthcare Finance and the American Journal of Managed Care.

Heart Disease

Research!America board member Nancy Brown, CEO, American Heart Association, was quoted in a Cardiovascular Business article about a partnership between the American Heart Association and Lawrence Livermore National Laboratory to help speed drug discovery through the use of computational and experimental tools.

Medical Device Tax

Research!America Vice President of Policy and Advocacy Ellie Dehoney penned an op-ed in The Morning Consult urging Congress to repeal the medical device tax. “…R&D, including the R&D behind new medical devices, gives a fighting chance to children with EB and others facing life-threatening diseases. We undervalue it at their peril.”

An Inside Health Policy article about calls to repeal the medical device tax quoted Mary Woolley. “By disincentivizing investment in medical device R&D, the medical device tax works against progress toward new medical technologies that can save lives and provide transformative support to individuals with disabilities.”

Cancer Treatments

Research!America board member Susan Dentzer, president and CEO, Network for Excellence in Health Innovation (NEHI), was quoted in The American Journal of Managed Care about a new white paper from NEHI that encourages the use of outcomes-based contracting for novel oncology drugs. “We are in the midst of a revolution in cancer care in which new, more personalized drugs will help many patients, but at high cost.”

IN BRIEF

- The L’Oreal USA For Women in Science fellowship program is accepting applications through February 2, 2018.
  http://bit.ly/2jpcr9a
- Nominations are open through January 12 for the National Organization for Rare Disorders 2018 Rare Impact Awards.
- Elias Zerhouni, M.D., president of Sanofi R&D and Research!America board member, was awarded “Executive of the Year” at the 13th Annual Scrip Awards.
- The Association for Research in Vision and Ophthalmology released a report this week illustrating how the imaging technology OCT has saved taxpayers billions of dollars.
Pathways to Progress: Combating the HIV/AIDS Epidemic

An effective vaccine combined with implementation of current scientific tools “could be the nail in the coffin for HIV” in 10 years, said Anthony Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases. But the amount of progress made depends largely on the political, economic and financial commitment of the entire world, he added.

Fauci was among the panelists at The Washington Post’s December 5 discussion “Pathways to Progress: Combating the HIV/AIDS Epidemic.” The epidemic killed 1 million people worldwide in 2016, according to the Centers for Disease Control and Prevention.

Deborah Birx, M.D., Ambassador-at-Large and global AIDS coordinator and special representative for global health diplomacy at the U.S. Department of State, said communication is also key to stopping the epidemic.

“We have millions of people still dying and it isn’t in the press and it isn’t being discussed and it isn’t in the schools,” said Birx. “So 16-year-olds are becoming HIV positive who didn’t even know they were at risk.”

Awareness efforts, which should be led by community-based organizations, must tackle issues of stigma and discrimination that often prevent people from seeking care, said Gregg H. Alton, JD, executive vice president, corporate and medical affairs, Gilead Sciences, Inc., which sponsored the event.

Dionne Warwick, Grammy award-winning musician and long-time HIV/AIDS activist, said educating the public about HIV/AIDS – and reaching young people in particular – means meeting them where they are. She cited, as an example, the effective use of television ads and comic books to educate teenagers early in the epidemic.

“We have to be advocates for ourselves, our neighbors, our neighbors’ children,” said Warwick.

Visit http://wapo.st/2B1iR95 for video of the event.

Overcoming Challenges in Science Communication

Scientists shared innovative approaches to engaging the public on complex scientific issues at the National Academy of Sciences’ Sackler Colloquium on the Science of Science Communication III on November 16-17 in Washington, D.C.

The theme, “Inspiring Novel Collaborations and Building Capacity,” focused on the NAS study Communicating Science Effectively: A Research Agenda to advance both research and practice in science communication. The report offers a research agenda for science communicators and researchers seeking to apply this research and fill gaps in knowledge about how to communicate effectively about science, focusing on issues that are contentious in the public sphere. To inform this research agenda, the report identifies important influences – psychological, economic, political, social, cultural and media-related – on how science related to such issues is understood, perceived and used.

The study’s committee chair Alan Leshner, Ph.D., CEO Emeritus, American Association for the Advancement of Science and Research!America board member, told attendees that scientists need to “move from a monologue to a dialogue” with the public.

Researchers from Dartmouth College and practitioners from the Vermont Department of Health, award recipients, described their study focused on communicating the benefits of vaccines to hesitant parents.

Suzanne Ffolkes, vice president of communications, Research!America, joined other panelists to discuss ways to strengthen the project, such as engaging different segments of the population and influencers in local communities.

For more information on the NAS Sackler Colloquia, visit http://bit.ly/2An6HHi.
The National Rural Health Association (NRHA) is a national nonprofit membership organization with more than 21,000 members. The association’s mission is to provide leadership on rural health issues through research, advocacy, communications, and education. NRHA membership consists of a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health.

The obstacles faced by health care providers and patients in rural areas are vastly different than those in urban areas. Economic factors, cultural and social differences, educational shortcomings, lack of recognition by legislators and the sheer isolation of living in remote areas all conspire to create health care disparities and impede rural Americans in their struggle to lead normal, healthy lives.

For more than 40 years, the National Rural Health Association (NRHA) has been serving rural communities by advancing and publicizing rural health issues and seeking to solve rural health care challenges. NRHA is the only national organization with a clear mission to improve the delivery of health services in rural areas, helping rural citizens build, maintain, and improve the institutions that can meet their health care needs by providing research, education, leadership, and informational support.

NRHA’s activities bring together residents of rural communities, rural health professionals of all specialties, representatives of state, local and national governments and the full range of private sector rural health organizations. Our programs serve rural communities by providing relevant and timely information and best practices to all people who care about the health of rural America.

NRHA advocates for rural communities. Using the association’s legislative and regulatory policies and positions, NRHA advocates before Congress, the White House and federal agencies. The association serves as a primary rural resource to elected officials, policy leaders and other organizations on rural health initiatives and programs.

Through activities such as the annual Rural Health Policy Institute and ongoing grassroots campaigns and activities, NRHA members actively participate in advocacy efforts to bring about appropriate rural health policy and legislation. As an NRHA member benefit, the government affairs team holds monthly grassroots calls to inform members of what is happening in Washington to grassroots advocacy.

NRHA’s members set the policies and positions that NRHA advocates for at a national level. All members of the association can participate in the development of policy by submitting potential policy positions for consideration. Positions are then reviewed and approved by the Rural Health Congress, which is made up of a broad representation of members.

The policy papers and statements adopted by the Rural Health Congress are the background and support for NRHA’s Legislative and Regulatory Agenda, which reflects the mission and values of NRHA by highlighting issues of importance to our membership.

The NRHA fights for access to quality health care for rural Americans. “Since 2010, more than 80 rural hospitals have closed and counting. Right now, 673 additional facilities are vulnerable and could close – this represents over 1/3 of rural hospitals in the U.S.,” said Alan Morgan, CEO, NRHA. “If Congress doesn’t act, hundreds more could close, leaving hundreds of thousands of rural Americans without access to their local hospital.”

NRHA supports strong funding for the entire rural health care safety net. Mandatory, long-term funding for the Teaching Health Center and Rural Training Track professional training programs, the National Health Service Corps and the Community Health Center Fund is needed. Sustaining Medicaid primary care parity payments is critical to increasing access to providers for the rural poor. Increasing rural health clinics’ capitated payment rate will sustain these critical rural safety net providers as they treat new populations under health care reform.

For more information, visit www.ruralhealthweb.org.
Urge Congress to #RaisetheCaps

As Congress works on a final federal spending bill for FY18, the austerity level budget caps established under the 2011 Budget Control Act are once again in force after two-year reprieve. Unless Congress negotiates another agreement to lift these 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 to advance science and ensure the security, health and wellbeing of the American people.

Your input counts. Urge your representatives in Congress to #RaisetheCaps and invest in our nation’s science agencies. Tell them you want a federal budget that works for our nation.