Panelists Provide Straight Talk for 2013 National Health Research Forum

Research!America’s National Health Research Forum—held September 12 at the Newseum’s Knight Conference Center in Washington, DC—examined the current and future state of research to improve health. The theme was “Straight Talk About the Future of Medical and Health Research.”

Research!America’s president and CEO, Mary Woolley, and chair, The Honorable John Edward Porter, opened the program. Porter introduced Bart Peterson, JD, senior vice president of corporate affairs and communications at Lilly, who offered the keynote address.

The first panel, focusing on biomedical research and development, was moderated by journalist Eleanor Clift of Newsweek and The Daily Beast and featured John Crowley, president and CEO of Amicus Therapeutics and a patient advocate; William Hait, MD, PhD, global head of R&D at Janssen Pharmaceuticals; and Peterson. The discussion cen-

Panel 1: Eleanor Clift (left); Bart Peterson, JD; Margaret Hamburg, MD; John Crowley; and William Hait, MD, PhD.

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Doctors Should Educate the Public on Clinical Trials, Americans Say

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Federal government</td>
<td>17%</td>
</tr>
<tr>
<td>Doctors and other health care providers</td>
<td>41%</td>
</tr>
<tr>
<td>Insurance companies</td>
<td>6%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>16%</td>
</tr>
<tr>
<td>Patient organizations</td>
<td>4%</td>
</tr>
<tr>
<td>Not sure</td>
<td>16%</td>
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ACRO began as a trade organization designed to promote and represent clinical research organizations; little more than a decade later, ACRO is much more involved in advocacy and legislative and regulatory affairs. And it’s not just American regulatory affairs; the group keeps abreast of developments in Europe and emerging markets, like India, wherever its members do business.

“We’re being a little more proactive,” said John Lewis, ACRO’s vice president for public affairs, “having started out playing defense primarily.”

Though ACRO’s website lists a number of key issue areas, the most pressing domestic issue over the past several years has been taxation. One particular concern was tax repatriation legislation, since ACRO’s members are mostly U.S.-based but roughly half of their revenues come from outside the U.S., Lewis said. ACRO’s members are also engaged with certain tenets of the R&D tax credit.

“In other countries—the U.K., France, Canada, Austria, a number of other countries—CROs can claim an R&D tax credit,” Lewis said. “... And there are many factors, but we think that’s one of the factors why more research is being done outside the United States.”

According to clinicaltrials.gov, as recently as 2008, about 53% of industry-sponsored clinical trials were conducted in the United States. That percentage dropped to about 47% in 2012.

Being a member of a respected organization like Research!America enables ACRO to leverage its public policy messaging around the promotion of medical research. Membership also opens up opportunities to participate in Research!America’s polls, such as the recent one on public attitudes toward clinical trials.

“By being able to partner with Research!America on the clinical trials poll, we could draw a broader audience for our core issue. We subsequently shot videos with Mary Woolley, which added great content for our YouTube channel, and we are now discussing a Hill briefing on clinical trial participation,” Lewis said. “So, from ACRO’s perspective, we were able to co-sponsor important research, boost our communications activities and take our message to Congress. This is a great ‘return on investment’ from our membership.”


Research!America Adds Value

Research!America stands on a reputation of innovative advocacy that generates results serving our mission and the interests of our members:

- Research!America’s Advocacy Awards celebrate the efforts of those who have made a difference in advocating for or increasing awareness of the role of health and medical research.
- Our National Health Research Forum brings together thought leaders from throughout the research world to examine the current and future landscape of research to improve health.
Government Shutdown

Bloomberg BNA, CQ Healthbeat and CIDRAP News quoted Research!America President and CEO Mary Woolley about the consequences of a government shutdown to medical and health research. “It’s inconceivable that our nation’s research ecosystem, the catalyst for addressing current and emerging health threats, is being hamstrung by the inability of our elected officials to reach a budget agreement and end indiscriminate, across-the-board budget cuts,” she said.

Research!America Board member Georges Benjamin, MD, executive director of the American Public Health Association, told MSNBC and Modern Healthcare that the association was opposed to a piecemeal approach to funding government agencies.

2013 National Health Research Forum

Research!America’s National Health Research Forum, “Straight Talk About the Future of Medical and Health Research,” featured leaders from government, industry, academia and patient advocates discussing opportunities and challenges facing biomedical and health research. The forum received significant press coverage from CQ Healthbeat, FDA News, Medscape, ScienceInsider, The Pink Sheet Daily, Politico Pro and WebMD. The event was live streamed on WebMD, and several Research!America members covered the event on blogs and social media channels.

Improving Science Education

Research!America Board member Alan Leshner, PhD, CEO of the American Association for the Advancement of Science, was featured in a round-up article about ideas for improving science education in The New York Times. In the piece, he pointed out the need for teachers to be “personally immersed in science.”

U.S. Scientists Consider Moving Overseas

Research!America President and CEO Mary Woolley was interviewed by Chemistry World about scientists who are considering moving overseas because of sequestration and other funding challenges in the U.S. “Other nations that are attractive to U.S. scientists,” Woolley said, “now include those whose governments have committed to science, even in a time of general economic austerity: the United Kingdom, Singapore, Sweden and Australia.”

Funding Cuts Hurt Research

Paul E. Klotman, MD, president and CEO of Baylor College of Medicine in Houston, and Adam Kuspa, PhD, senior vice president for research at BCM, wrote an op-ed for The Huffington Post calling on policy makers to prioritize research. “Don’t shortchange the science that can lengthen lifespans,” Klotman and Kuspa wrote. An op-ed by American Heart Association President Mariell Jessup, MD, describing the importance of lifesaving research was also published in The Huffington Post. And The Endocrine Society’s president, Teresa Woodruff, PhD, had a letter to the editor published in The New York Times about the need to protect medical research funding.

In an Inside Higher Ed article, Thomas Michel, MD, PhD, a professor of medicine and biochemistry at Harvard Medical School, lamented the damaging effects of research budget cuts on young researchers. “I fear that we’re going to be losing a generation of bright young scientists who might take their talents in other directions,” he said.
The ongoing government shutdown—which began October 1 when the House and Senate failed to agree on FY14 appropriations—continues to hurt the country’s research agencies. Employees at the National Institutes of Health and other federal health agencies have been furloughed, disrupting critical research and public health programs.

Rep. Jack Kingston (R-GA), chair of the House Appropriations Labor-H subcommittee, sponsored legislation to restart the NIH, but Democratic leaders in the Senate have rejected such piece-meal appropriations bills. The House had previously voted on bills to supply appropriations for veterans health programs, national parks and museums, and other government activities.

Just as flu season begins, flu tracking efforts at the Centers for Disease Control and Prevention are among the many programs affected by the shutdown. Just under half of the employees at the Food and Drug Administration have been furloughed, curtailing food safety inspections and much of its laboratory research. Grant applications and payments at NIH, the National Science Foundation, and the Agency for Healthcare Research and Quality have also been affected.

House Republicans have insisted that any appropriations bills include language to eliminate all or parts of the Affordable Care Act, a non-starter for the Democratically controlled Senate and President Barack Obama. It seems increasingly likely that appropriations for FY14 and the debt ceiling—which the country is expected to reach in mid-October—will be dealt with simultaneously.

**CPH Foundation Update**

The CPH Foundation is holding its 4th annual Unsung Heroes of Public Health awards again this year with an application deadline of November 1. We are especially grateful to AbbVie for acting as our sponsor of this year’s event. Don’t forget to nominate leaders in the public health field for one of our three awards. Visit www.CPHFoundation.org to read about past winners and to download a nominations form.

As a result of the shutdown of the federal government, the CDC was forced to furlough 6,000 of their 9,000 staff just days before the CPH Foundation’s planned tour of the CDC for Members of Congress. CPHF and CDC’s leadership made the call to postpone the tour as the funding crisis dragged on. A second tour of the CDC is now planned for November 8, and CPHF is working to rebook those who had signed up to join our original tour.

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**2013 Federal Research Budget**

<table>
<thead>
<tr>
<th>Agency</th>
<th>FY12 Actual</th>
<th>FY13 Post-Sequestration</th>
<th>FY14 Senate’s Request</th>
<th>FY14 President’s Request</th>
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<tbody>
<tr>
<td>National Institutes of Health</td>
<td>$30.7 billion</td>
<td>$29.1 billion</td>
<td>$30.9 billion</td>
<td>$31.0 billion</td>
</tr>
<tr>
<td>Centers for Disease Control and Prevention*</td>
<td>$5.7 billion</td>
<td>$5.4 billion</td>
<td>$5.8 billion</td>
<td>$5.2 billion</td>
</tr>
<tr>
<td>Food and Drug Administration</td>
<td>$2.6 billion</td>
<td>$2.5 billion</td>
<td>$2.6 billion</td>
<td>$2.6 billion</td>
</tr>
<tr>
<td>National Science Foundation</td>
<td>$7.0 billion</td>
<td>$6.9 billion</td>
<td>$7.4 billion</td>
<td>$7.6 billion</td>
</tr>
<tr>
<td>Agency for Healthcare Research and Quality**</td>
<td>$0.37 billion</td>
<td>$0.35 billion</td>
<td>$0.36 billion</td>
<td>$0.35 billion</td>
</tr>
</tbody>
</table>

* CDC core budget

** Excludes funding from transfers
Rally for Medical Research Holds Hill Day

On September 18, more than 170 organizations and institutions from the medical research advocacy community met with House and Senate offices in Washington, DC, to urge Congress to invest in the National Institutes of Health for the health and economic security of our nation.

Research!America Chair and former Congressman John E. Porter fired up the Rally for Medical Research Hill crowd minutes before the meetings: “When you visit Members of Congress and staff tell them about the progress that has been made through federal investments in research—past, present and imagine the possibilities. Tell them about the scientific opportunities that have never been greater. Tell them about looming threats, like antibiotic-resistant bacteria, that simply cannot wait. Tell them about jobs and growing the economy, which will be derived from investments in medical research, creating an educated workforce and high-tech, high-paying jobs and the importance of STEM education,” he said.

AACR Releases Latest Cancer Progress Report

The American Association for Cancer Research’s Cancer Progress Report 2013 finds that cancer deaths are falling, while the number of survivors and approved treatments continues to grow. Further progress, however, is hindered by the obesity epidemic and continued tobacco use; both lead to elevated risk for several different types of cancer.

Another hindrance is stagnant funding and sequestration at the National Institutes of Health. The report notes that cancer research is all the more critical because of the growing number of Americans over age 65 who will live longer and likely require cancer treatment in the next 20 years.

Read the full report at http://cancerprogressreport.org.
Lasker Foundation Announces 2013 Award Winners

The Albert and Mary Lasker Foundation has announced the winners of the 2013 Lasker Awards. Richard H. Scheller, PhD, executive vice president of research and early development at Genentech, and Thomas C. Südhof, MD, professor at the Stanford University School of Medicine, received the Albert Lasker Basic Medical Research Award. Graeme M. Clark, PhD, professor emeritus of the University of Melbourne in Australia; Ingeborg Hochmair, PhD, founder and CEO of MED-EL in Innsbruck, Austria; and Blake S. Wilson, professor at Duke University, received the Lasker-DeBakey Clinical Medical Research Award. Bill Gates and Melinda Gates will receive the Lasker-Bloomberg Public Service Award for their inspiring philanthropy to address the most pressing global health concerns.

“The Lasker Awards showcase the power of biomedical research to advance science, save lives and avert suffering the world over,” said Alfred Sommer, MD, chair of the Lasker Foundation’s board of directors, in a statement.

Final Golden Goose Award Winners Announced; Ceremony Held

The final 2013 Golden Goose Award winners were announced just before a mid-September ceremony to honor the scientists and their achievements. The winners included Thomas Brock, PhD, and Hudson Freeze, PhD, whose discovery of bacteria at Yellowstone National Park led to widespread advances in biotechnology and genomics. Their work was funded by the National Science Foundation. Alvin Roth, PhD; Lloyd Shapely, PhD; and the late David Gale, PhD, were also honored for their work in economics and mathematics that led to the development of today’s kidney donor matching program.

Those winners, along with previously announced winner John Eng, MD, were honored at a ceremony on Capitol Hill in Washington, DC, on September 19.

Americans Admire Organ Donors, Those Who Give Blood

How much do you admire the following groups of people on a scale of 1 to 4, with 1 being not at all and 4 being a great deal?

<table>
<thead>
<tr>
<th>People who donate an organ:</th>
<th>69%</th>
<th>19%</th>
<th>3%</th>
<th>2%</th>
<th>7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>People who give blood:</td>
<td>61%</td>
<td>26%</td>
<td>4%</td>
<td>3%</td>
<td>7%</td>
</tr>
<tr>
<td>People who volunteer for clinical trials:</td>
<td>37%</td>
<td>38%</td>
<td>9%</td>
<td>4%</td>
<td>13%</td>
</tr>
</tbody>
</table>

SOURCE: A RESEARCH!AMERICA POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN MAY 2013. (DUE TO ROUNDING, TOTALS DO NOT ADD TO 100%).
Report: Vaccines Have Eradicated 90% of 10 Infectious Diseases in the U.S.

PhRMA has released a report on the prevention and treatment of disease through vaccines. As stated in the report, “according to data from the Centers for Disease Control and Prevention, 10 infectious diseases have been at least 90% eradicated in the United States thanks to vaccines.” The report also examines how biopharmaceutical research companies are developing more than 270 vaccines for a vast spectrum of illnesses including infectious diseases, cancer, neurological disorders and allergies. The report also includes a synopsis of the path that drugs take from development to approval: A single new medicine takes an average of 10 to 15 years, and for every 5,000 to 10,000 compounds being studied in the development pipeline, only one is approved. PhRMA member companies invested an estimated $48.5 billion in research and development in 2012.


Research Australia Releases 2013 National Public Opinion Poll

The 2013 public opinion poll conducted by Research Australia reveals strong support for funding health and medical research. Respondents were asked how the Australian federal government should focus its priorities for the next two to three years—providing an interesting backdrop for the country’s recent parliamentary elections—and three significant health issues ranked highly in the results: improving hospital and health care systems, increasing funding for health and medical research, and increasing funding and programs for preventative health care. Most of the findings in the poll are consistent with the findings of Research!America’s polling regarding the importance of health and medical research in improving the health care system, addressing health and economic challenges, and sharing personal health data.

To view more results from the poll, visit www.researchaustralia.org/advocacy-publications/public-opinion-polls.

Research!America Joins CSBI

Research!America has joined the Coalition of Small Business Innovators, a group dedicated to stimulating sustained, private investment in small, highly innovative companies focusing on the development of new technologies.

“Our principles of advocating for strong policies that support furthering medical, health and scientific research are in line with CSBI’s goals, and we are excited to join the effort,” said Mary Woolley, president and CEO of Research!America.

Research!America members who are also part of the coalition include AdvaMed, the Association of Clinical Research Organizations, the Biotechnology Industry Organization and the Medical Device Manufacturers Association.

Am er i ca S p e a k s

Fewer than 10% of Americans participate in clinical trials. Which of the following do you think is a reason that individuals don’t participate in clinical trials? (multiple responses allowed)

Not aware/lack of information 53%
Lack of trust 53%
Too risky 51%
Adverse health outcomes 44%
Little or no monetary compensation 35%
Privacy issues 27%
Too much time 27%
Not sure 11%

Source: A Research!America Poll of U.S. Adults Conducted in Partnership with Zogby Analytics in May 2013.
We are continuing our successful social media campaign, urging policy makers to fund research and medical innovation at robust levels, on Facebook and Twitter using the hashtag #curesnotcuts. We encourage you and your organization to join our campaign or start your own! For more advocacy ideas, go to www.SaveResearch.org or read our advocacy tips at www.researchamerica.org/effective_advocacy.
2013 National Health Research Forum
Straight Talk About the Future of Medical and Health Research

September 12, 2013
Knight Conference Center at the Newseum
Washington, DC

Research!America extends grateful thanks to our 2013 National Health Research Forum Sponsors:

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“Steven Salzberg … said that he had received about 20% less in federal funding than his peers than what was recommended for his work on the biological underpinnings of cancer and other diseases. And here is the money quote, ‘Less science is getting done. That means cures won’t emerge. Five years from now, when your aunt gets cancer and you can’t do anything for her, people won’t stop and think … if we only hadn’t had the sequester.’ Well, we have the sequester, and it’s up to everybody to try figure out how to make do in this brave new world.”

MODERATOR: ELEANOR CLIFT, contributing editor, Newsweek; contributor, The Daily Beast

“The challenge has been since 2008, 2009, the financial crisis and so many changes in the world that we’ve had a risk-off mentality. And that really shook the foundations of biomedical research: not as many funds for government, not as many funds in academic research, venture capital and to startup companies basically drying up, and we were in a crisis in 2010.”

JOHN CROWLEY, JD, MBA, president and CEO, Amicus Therapeutics; patient advocate

“Our role is not only to work with the scientific community both in academia and in industry to really identify where are the promises in science and technology today and how can we leverage them into real-world products. How can we do the research from the very beginning in ways that support the regulatory requirement and enable us to really make the best use of now increasingly limited dollars as we build on discoveries and move them across the finish line into the products that matter for people?”

MARGARET HAMBURG, MD, commissioner, Food and Drug Administration

“The people who come at training don’t see this as a career. And if you lose these kids who are so smart and so talented, who’s going to be the next generation that continues to spur on biomedical research and the prevention and cures we seek in this country? The pharmaceutical companies will look everywhere in the world … But we want to see as Americans the U.S. to continue to be the leaders. And what I’m seeing, because of a variety of factors, we’re losing that generation, and that’s a real problem.”

WILLIAM HAIT, MD, PHD, global head, Janssen Research & Development

“Historically, patients were somewhat dismissed as not being sophisticated enough … And the reality is this is not true anymore. Patient advocacy groups have become very sophisticated, very much at the cutting edge of scientific research and have a voice that I think can be more powerful than any other voice in pushing us forward, pushing us beyond what we might think we can do when we look at things from our own silo point of view.”

BART PETERSON, JD, senior vice president, corporate affairs and communications, Lilly

SAVE THE DATE:
NATIONAL HEALTH RESEARCH FORUM
SEPTEMBER 11, 2014
WASHINGTON, DC
“There were actually people out there who are fighting, Dr. Conway and Dr. Frieden, on many issues with regards to people being educated more in prevention and methodology and behavior. It’s a slippery slope, don’t get involved, big brother’s coming down.”

MODERATOR: MICHELLE MILLER, CBS News correspondent

“We took a lot of heat for readmission incentives and quality improvement. I’ve got a control chart on my wall: 19% to 20% [readmission rates] for decades in the Medicare population, now below 18%. That’s over 100,000 Medicare beneficiaries every year staying home and healthy instead of being in the hospital.”

PATRICK CONWAY, MD, acting director, Center for Medicare & Medicaid Innovation

“[Prevention and prevention research] is truly the best buy in the health care system ... we have a great return on investment. And that return on investment is in terms of pure illnesses, pure deaths, a decrease in health care-associated infections, which we’re already seeing a payoff from economically. And ultimately and most important is the physician I would say, a payoff in terms of better health and longer more productive lives.”

TOM FRIEDEN, MD, MPH, director, Centers for Disease Control and Prevention

“Former Congressman Patrick Kennedy … made a wonderful statement. He says, ‘If you’re walking down the street and you see somebody lying there and it looks like they’ve had a heart attack. What do you do? Call 911,’ he said … everybody cheers because we’re really taking advantage of the great medical technology and care that we’ve developed in this country over the years. But if you are walking down the street and somebody is lying there and they’re mumbling. What do you do? Most people,’ he said, ‘walk around them.’”

JAY GERSHEN, DDS, PHD, president, Northeast Ohio Medical University

“A retrospective analysis of data from 2000 to 2008 … looked at people who came into the hospital and got admitted for a dental abscess, and during that time period, almost 62,000 admittances. Almost all of them were through the emergency room. And during that same time period, about 65 people died because of that complication … Why did they even have the abscess in the first place? Why aren’t we doing the things that we should from a preventative standpoint, from a public health standpoint, to actually prevent these very treatable, very preventable diseases to begin with?”

FOTI PANAGAKOS, DMD, PHD, global director, scientific affairs, Colgate-Palmolive

“What’s important in our national discourse is to not pit one type of science against another type of science for us to benefit for our health and our health care to actually catch up … with some other countries. If you saw the Institute of Medicine’s report on shorter lives, poorer health, for all the innovation, for all the resources we do have, we do not deliver what we could. And so, I think we need to really commit to working together to have all of this type of research supported adequately because it will only get worse.”

LISA SIMPSON, MB, BCH, MPH, president and CEO, AcademyHealth
“We lose sight of any of the priorities. There’s no debate, no deliberation and no setting of priorities. And the anti-government fervor is let’s cut, except when you get to specifics … Well, we didn’t mean pediatric research, we meant everything else. Well, we didn’t mean the FDA, we meant everything else … I think we’re going to have to devote some time and effort to pushing people into realizing that the votes that they’re taking actually are cutting some of these things that most Americans also want but don’t believe is a part of the government. They’re saying cut government without realizing what government is. And we’re going to have to change that dialogue.”

MODERATOR: NORMAN ORNSTEIN, PHD, resident scholar, American Enterprise Institute; contributing editor, National Journal and The Atlantic

“So how is it that we can disconnect the politicization of this conversation and really get focused on the essence that it provides, both for the betterment of society but more importantly for the global economic power that this industry brings to this country? It’s a simple, elegant and beautiful argument, and one of the best value-creating industries in the world. And it should be that simple, that transparent for everyone that’s six blocks away.”

TONY COLES, MD, chairman and CEO, Onyx Pharmaceuticals

“For us to sit in a room like this and basically say, ‘Well, you know, it’s the way politics goes.’ It’s just unacceptable. If we really believe that this is a noble enterprise that we’re engaged in something that is as important as the health of you and your family and of the rest of the nation, and if it’s the way we’re going to pull our economy back out of some difficult spots, which the evidence is very strong for, we should be making a lot of noise. So, make noise, people. I’m making noise. Come along, help me out.”

FRANCIS COLLINS, MD, PHD, director, National Institutes of Health

“When I talked to people like me now when I was 40 years ago I don’t think their level of excitement, that level of great expectation from this country, is there. So I’m really worried about that. And then if you put on top of that our faculty who is working really hard, you know, many of them are in fact in the category of trying to rewrite the grants and … they find they spend more time writing grants than doing the research which is absolutely needed.”

VICTOR DZAU, MD, president and CEO, Duke University Health System; chancellor for health affairs, Duke University

“I’d see this truly as a community and as a community, I don’t think we’ve been as effective at communicating together in a unified way. Because the benefactors of what we do, or the community at large, clearly there’ll be the stakeholders who are putting their speculative dollars behind the development that occurs in the industry. But the reality is we have allowed the politicization of this topic because there’s been controversy or divide within this community.”

ROBERT HARIRI, MD, PHD, CEO, Celgene Cellular Therapeutics

“We have different harmonic lines in what we sing to the same hymnal. But the one that needs to rise to the top is this era and age of patient centricity. And we are in it. I almost felt like I want to say thank you for including me on the panel as a voice of the patient, and when I thought about those words I realized those were words of 1992 when I landed on an NIH advisory council, and I was grateful as a patient to be there. Today, I shouldn’t be grateful to be at the table, I should know that the voice that I represent is the voice that is setting the table and is getting ready to design the menu.”

DEBRA LAPPIN, JD, principal, FaegreBD Consulting; patient advocate