

The Research ADVOCATE

JUNE 2007

Bringing Research Closer to Home

Congress Receives Your Congress–Your Health Surveys

Members of Congress were asked last month where they stand on health and research, as part of *Your Congress–Your Health*, a new initiative from Research!America, the **Albert and Mary Lasker Foundation** and a growing list of partners.



Your Congress.
Your Health.

All members of Congress have been asked to complete a brief questionnaire seeking their positions on a range of research and health issues.

The initiative is being promoted with advertisements in Capitol Hill publications *Roll Call*, *The Hill* and *The Politico*. But requests from constituents will have more effect at swaying members of

Congress to complete the questionnaire. *Visit www.yourcongressyourhealth.org and encourage your Congressional delegation to respond.*

Voters rate the importance of finding cures to diseases as a top national issue, ahead of dealing with illegal immigration and combating terrorism, according to a recent public opinion poll from the **Biotechnology Industry Organization**, a Research!America member.

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Policy Makers Meet with Rogers Society Ambassadors

Jonathan Stivers, senior adviser to **House Speaker Nancy Pelosi (CA)**, met last month with **Michael Cappello, MD**, a Paul G. Rogers Society for Global Health Research Ambassador from Yale University, to discuss the strong public support for increasing U.S. efforts to improve the health of people living in developing countries. Cappello explained ways health research can

make a lasting impact on seemingly intractable problems.

In Tennessee, state senators **Rusty Crowe** and **Douglas Henry** and state representatives **Joe Armstrong** and **Brenda Gilmore** met with Society Ambassadors **James E.K. Hildreth, PhD, MD**, Meharry Medical

PAUL G. ROGERS
SOCIETY



College; and **Sten H. Vermund, MD, PhD**, and **Peter F. Wright, MD**, of

Vanderbilt University Medical Center. The Ambassadors emphasized the leadership their global health research efforts are garnering for Tennessee. Media meetings included the *The Tennessean*

editorial board, which resulted in two May 27 editorials and columns by the Ambassadors.

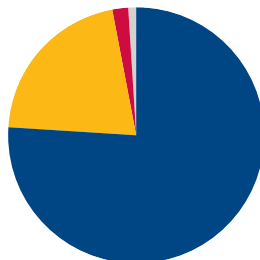
Ambassadors **C. Ross Anthony, PhD**,

Continued on page 6

AMERICA Speaks

U.S. Should Be Global Leader in Scientific Research

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



Very	76%
Somewhat	21%
Not	2%
Don't know	1%

New ON THE Web

www.researchamerica.org

Check out our newest initiative, **Your Congress—Your Health**, and urge your representative and senators to respond at www.yourcongressyourhealth.org.

The **Centers for Disease Control and Prevention** has launched its redesigned home page. See www.cdc.org.

The **Federation of American Societies for Experimental Biology**, a *Research!America* member, recently released Federal Funding for Biomedical and Related Life Sciences Research, FY 2008. View the report at http://opa.faseb.org/pdf/final_funding_fy2008.pdf.

Our **chronic fatigue fact sheet**, the latest in our *Investment in Research Saves Lives and Money* series, is this month's insert and is available on our Web site.

The Research ADVOCATE



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About Research!America

Research!America is the nation's largest not-for-profit public education and advocacy alliance working to make research to improve health a higher national priority. Founded in 1989, Research!America is supported by our 500+ member organizations that represent the voices of more than 125 million Americans. Our public opinion polls, advocacy programs and publications reach the public and decision makers to help advance medical, health and scientific research.

Research!America
AN ALLIANCE FOR DISCOVERIES IN HEALTH®

Members TAKE Action



Joan Rachlin, JD, MPH

Public Responsibility in Medicine and Research

Public Responsibility in Medicine and Research (PRIM&R) is dedicated to creating, implementing and advancing the highest ethical standards in the conduct of research.

PRIM&R, an international non-profit organization, has played a significant role in advancing medical research for almost 35 years and works closely with hundreds of research institutions as well as with the top federal regulatory agencies. The group's principal advocacy strategy is to educate all of the parties involved in the research process about their roles and responsibilities.

"PRIM&R's board and membership feel strongly that ethical research is scientifically responsible research, and yet too often research ethics are either minimized or entirely ignored," said **Joan Rachlin, JD, MPH**, PRIM&R's executive director. "Our work has helped prevent the kinds of tragedies and atrocities that eroded the public's trust in clinical and other research—for example, the Tuskegee Study of Untreated Syphilis in the Negro Male, Willowbrook Hepatitis Experiments, the Jewish Chronic Disease Hospital Cancer Experiments and research associated with the death of Jesse Gelsinger.

"We believe that when research is unethically or improperly conducted it's usually a result of ignorance rather than malevolence. As everyone involved with research becomes more educated about ethical issues and principles, they become advocates who can then positively influence subject protections at their respective institutions. We have worked hard to create a cadre of educated, committed and informed frontline subject advocates."

Most of the institutions at which PRIM&R members work receive their primary funding from the National

Institutes of Health, so there is great concern about NIH appropriations.

"When there's less federal money available for research, there is consequently less money available for education about research and research ethics," Rachlin said. "Also, if NIH is not adequately funded, more research will take place in countries without fully developed infrastructures in place for protecting human subjects."

One of PRIM&R's greatest challenges has been convincing researchers that learning about and applying ethical principles is worth their time. Rachlin said PRIM&R's membership in Research!America helps enhance its outreach and communications so more institutions can know about the importance of promoting ethical research.

"Good ethics is good science, and the two dimensions of research cannot independently exist," Rachlin said. "When even the most resistant scientists have attended our conferences they end up being grateful they did."

PRIM&R is redesigning its Web site, to better serve its 2,700 members by including more member-focused information and resources.

Its 2007 Annual Human Research Protection Programs Conference will be December 1-4 in Boston. The meeting promises to provide the same high-quality offering as its predecessors, and there will be pre-conference courses for those needing orientation or a refresher.

For more information, including the conference program, visit www.primr.org.

Calling for NIH Funding Growth

A new ad campaign led by Research!America member **Invitrogen** urges Congress to boost FY08 funding for the NIH to \$30.8 billion. Running in Capitol Hill-focused publications, the ad bears the logos of the **Association of American Medical Colleges, Biotechnology Industry Organization, Association of American Universities, Campaign for Medical Research, BIOCOM, California Healthcare Institute, Federation of American Societies for Experimental Biology** and Research!America.

A May 4 *Washington Times* editorial (“Unhealthy Cuts”) calls for more NIH funding as “an investment in our collective future. It underwrites basic research that, in many cases, the private sector cannot or will not undertake.” However, the editorial suggests a loss of public interest as contributing to recent years’ flat funding. A letter from Research!America’s **Mary Woolley**, published May 7, argues, “Americans recognize the importance of NIH and other agencies and how their funding fuels our medical and health research pipeline.” Visit www.researchamerica.org to read the editorial and letter.

Science addressed the “Boom and Bust” cycle of NIH funding (April 20). Among those interviewed was Research!America board member **Mary J.C. Hendrix, PhD**, of Chicago’s Children’s Memorial Research Center. The article says, “Hendrix, one of the leadership group who met years ago to look beyond the NIH doubling, favors boosting public-private partnerships and working more closely with disease foundations.”

The State of Philanthropic Research Dollars

Nature focused on philanthropic funding of medical research (May 17), noting that the past decade has seen this grow to a “grand scale.” Woolley is quoted on the contributions of private- and government-funded research. *The Wall Street Journal* picked up her comment in its May 18 print edition and blog.

The Importance of Framing Science

In a recent *Science* article, **Matthew Nisbet** of American University and science reporter **Chris Mooney** describe the value of “framing” science for the public: “Frames pare down complex issues by giving some aspects greater emphasis. They allow citizens to rapidly identify why an issue matters, who might be responsible and what should be done.” The piece concludes, “As unnatural as it might feel, scientists should strategically avoid emphasizing the technical details of science when trying to defend it.”

Global Health Research in Tennessean Editorials

The (Nashville) *Tennessean* newspaper devoted much of its May 27 Sunday “Issues” section to global health research, including first-person columns by three Ambassadors in our Paul G. Rogers Society for Global Health Research—**James E.K. Hildreth, PhD, MD**, of Meharry Medical College and Vanderbilt University Medical Center’s **Sten H. Vermund, MD, PhD**, and **Peter F. Wright, MD**.

Alzheimer’s Campaign Paints the Real Picture

The **Alzheimer’s Association**, a Research!America member, has launched a public education campaign to combat myths and complacency about the disease and encourage Americans to become Champions against Alzheimer’s. Visit www.actionalz.org.

We can't win the race against diseases if spending on NIH research lags behind.

2007 GDP: \$13.5 trillion
2007 NIH: \$25.5 billion
2008 NIH: \$25.5 billion

Improve the Odds for Cures.
Put NIH Research Funding Back on Track.

invitrogen AAMC Bio



Michael Moore’s documentary on the problems of health care will soon be in the news.

One potential presidential candidate, Fred Thompson, has already filmed his own rebuff. Whether on or off camera, every candidate and all members of Congress are well aware that the public wants health care improved and is running out of patience with elected officials’ inaction.

We are working to assure research for health is at the table when health care reform is under consideration. A vital tool in accomplishing this is **Your Congress—Your Health**, which will provide Americans with Congress’ views on key issues related to health care reform, including research. (Our thanks to Sen. Barack Obama (IL) for being first to pledge to respond and to Rep. Vernon J. Ehlers (MI) for being first to respond.)

I am asking everyone who reads this to do two things, right now. First, go to www.yourcongressyourhealth.org and click “For Constituents.” It will help you ask your delegation to complete the questionnaire. This will take less than a minute! Second, urge 10 people you know to do the same thing—your family, friends and colleagues should all find it in their interest and worth their time. (For those concerned about the appearance of lobbying—a voter asking an elected official to weigh in on an issue is NOT lobbying.)

PARADE magazine will soon be urging its 74 million readers to consult this site as discussion of the future of health care heats up. If stakeholders in research for health don’t weigh in now, research won’t be at the table when it counts. Please act now!

Mary Woolley

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FY08 Budget Resolution Adopted Strong Outreach by Advocates Essential

The House and Senate adopted the congressional FY08 budget of \$2.9 trillion on May 17. This includes \$21 billion more for non-defense discretionary spending than **President Bush** proposed. While the budget resolution does not require the President's signature, a confrontation between Congress and the White House is all but certain. The Office of Management and Budget has informed House and Senate budget leaders that it will advise the President to veto any appropriations bills exceeding his budget recommendation.

Congress will likely approve a Labor, Health, Human Services and Education appropriations bill with more funding than the President proposed, but overriding a veto will require strong, consistent outreach by the research advocacy community. At least 50 House Republicans and 17 Republican Senators would need to vote against the President to assure a veto-proof L-HHS bill.

Another letter of support for NIH was circulated in the House recently. **Rep. Brian Bilbray (CA)**, a co-chair of the **Congressional Biomedical Research Caucus**, initiated the letter, which includes signatures of co-chairs **Michael Castle (DE)**, **Lois Capps (CA)** and **Rush Holt (NJ)**. The letter called

on House members to make NIH funding a national priority.

Momentum Builds for Stem Cell Research

The House will vote on the Senate-passed version of the **Stem Cell Research Enhancement Act (S. 5)** in early June. A second vote is necessary because the Senate version differed from the House version (H.R. 3). Passage of S. 5 by the House would allow Congress to send the bill to President Bush.

Bush has promised to veto the bill, as he did in July 2006. He maintains that the executive order issued August 9, 2001, is the best policy. It limits federal funding for research on embryonic stem cells to those derived at the time.

One of the many state initiatives established in response to the federal policy is California's **Proposition 71**. In November 2004, Californians approved the measure to form the **California Institute for Regenerative Medicine** and fund \$3 billion in stem cell research over 10 years.

Opponents have filed law suits to prevent CIRM from issuing bonds to pay for the research. On May 16 the California Supreme Court refused to hear an appeal, clearing the way for CIRM to start issuing bonds. CIRM had been moving forward thanks to a loan from the state approved by **Gov. Arnold Schwarzenegger** and support from private donors.

2008 FEDERAL RESEARCH BUDGET

Agency	President's Request	% Change from 2007
National Institutes of Health	\$28.3 billion	-1.7%
Centers for Disease Control and Prevention*	\$5.8 billion	-4.4%
National Science Foundation	\$6.4 billion	+8.5%
Agency for Healthcare Research and Quality	\$330 million	+3.4%

* Reflects the CDC core program budget. For more information on the CDC budget, please visit www.FundCDC.org.

Public Health Leaders Meet With Pelosi



House Speaker
Nancy Pelosi (CA)

House Speaker Nancy Pelosi (CA) and her senior health and appropriations staffers met with **Campaign for Public Health** and other public health leadership on May 10, including **The**

Hon. John Edward Porter, chair of Research!America, **The Hon. Paul G. Rogers**, Research!America chair emeritus; **Georges Benjamin, MD**, American Public Health Association executive director; **Jennifer Luray**, senior director, government affairs and policy, Abbott Laboratories; **J. Michael McGinnis, MD**, senior scholar Institute of Medicine; and **Karl B. Moeller**, CPH executive director.

The **Centers for Disease Control and Prevention's** budget was detailed, highlighting the erosion of core program funding due to severe funding cuts to the agency since 2005 and the additional negative impact of inflation. Less than half of one percent of all federal health spending is allocated to CDC, while treatment costs are rising faster than inflation.

Moeller provided Pelosi a copy of the professional judgment budget CDC Director **Julie Louise Gerberding, MD, MPH**, prepared at the request of **House Appropriations Chair Dave Obey (WI)**. It states that CDC needs \$1 billion more in FY08

funding. Pelosi commended CDC for the important, comprehensive document. The group also provided an advance copy of the CPH-led sign-on letter with 500+ signatures supporting the professional judgment budget.

Public Health Study Group Engages Hill Staffers

The **Congressional Study Group on Public Health** met May 4 to focus on federal, state and private-sector public health efforts to reduce the prevalence of chronic diseases. **Janet Collins, PhD**, director, National Center for Chronic Disease Prevention and Health Promotion, CDC; **Mary T. Bassett, MD, MPH**, deputy commissioner, New York City Department of Health and Mental Hygiene; and **Mike Pucci**, executive vice president of external advocacy, GlaxoSmithKline, spoke at the briefing. For more, visit www.FundCDC.org.

Welcome New Members!

American College
of Sports Medicine

Association for
Psychological Science

Cystic Fibrosis Foundation

Duke University School of Nursing

Sudden Cardiac Arrest Association

*Not yet a member?
Join Research!America today!
E-mail cmccconnell@researchamerica.org*

Chronic Fatigue Syndrome Fact Sheet Part of National Awareness Campaign

More than one million Americans have chronic fatigue syndrome, yet the cause remains unknown. As part of our *Investment in Research Saves Lives and Money* series and in partnership with our member **CFIDS Association of America**, Research!America developed a fact sheet (see insert) that summarizes the economic impact of CFS and why more research is crucial.

CFS research advocates disseminated the fact sheet to policy leaders during a May lobby day, which was a component of CFIDS' 2006-07 national public awareness campaign sparked by **Centers for Disease Prevention and Control** support. The campaign also features a national traveling photo exhibit, "The Faces of Chronic Fatigue Syndrome." For more information, visit www.cfids.org/cfs.

Your Congress—Your Health

Continued from page 1

Your Congress—Your Health was introduced in a March issue of **PARADE** magazine and will be featured again in future issues. The magazine's 74 million readers were asked what health issues matter most to them. In response, **PARADE's** Web site received the highest number of comments of any article to date. This feedback was used to develop the survey for Congress.

Congress' responses will be posted at www.yourcongressyourhealth.org in mid-June. Visit the site now to see what questions we're asking Congress and return to see where they stand on these issues that affect us all.

The **American Academy of Nursing** and the **Kidney Cancer Association** have signed on as partners, joining **AARP**, the **Alzheimer's Association**, **American Association of Colleges of Nursing**, **American Association of Colleges of Pharmacy**, **Association of American Medical Colleges**, **Association of Schools of Public Health**, **The Endocrine Society**, **The Joseph H. Kanter Family Foundation**, **National Alliance for Hispanic Health**, **Pharmaceutical Research and Manufacturers of America**, **Revolution Health** and **Society for Neuroscience**.

Additional partners are welcome. For more information, e-mail Bill Leinweber, executive vice president, at bill@researchamerica.org. For more information about the BIO poll, see www.bio.org.

Principal Partner Thank You

Research!America thanks:

American Academy of Nursing
Burroughs Wellcome Fund
CFIDS Association of America
Clinical Research Forum
Mary J.C. Hendrix, PhD
Kidney Cancer Association
Lynn R. & Karl Prickett Fund

Did YOU Know

The **National Institutes of Health** recently welcomed four new members to the Director's Council of Public Representatives. The council advises the NIH director on issues in health care, medicine, community-based research and literacy programs. See <http://copr.nih.gov>.

The **Centers for Disease Control and Prevention** and the **University of North Carolina** are broadcasting "Public Health Grand Rounds," a series presenting case studies that emphasize CDC's health protection goals. The series, available via satellite and Web cast, will run from May through November. See www.cdc.gov.

Research!America's **Bill Leinweber** and **Karen A. Goraleski** conducted an advocacy training workshop at the **Clinical Research Forum's** annual conference in April. "Advocacy: Change at the National Level Begins With You" focused on the importance of scientists' voice in advocacy for research.

William D. Novelli, AARP CEO and Research!America board member, was the keynote speaker for the **Association for Research in Vision and Ophthalmology's** 2007 Annual Meeting in early May.

Rogers Society Ambassadors

Continued from page 1

of RAND; **Peter J. Hotez, MD, PhD**, of The George Washington University Medical Center; and **Les Roberts, PhD, MPH**, of Columbia University, spoke about global health research to high school students as part of a civic education program.

During a presentation to the **Baltimore City League of Woman Voters**, Ambassador **William B. Greenough III, MD**, of The Johns Hopkins University School of Medicine, asked the league to include in its health care resolution a note that "in the age of 'globalization,' research across political boundaries is essential to bring better health care at lower cost."

Global Health Funding Focus of Senate Hearing

U.S. Department of Health and Human Services **Secretary Michael Leavitt** said, "A healthy world is a good thing for America," during testimony before **Sens. Tom Harkin (IA)** and **Arlen Specter (PA)** at a May 2 Senate Appropriations subcommittee hearing on FY08 global health funding. "Health diplomacy must be the foundation of our foreign policy," Leavitt said.

Roger Glass, MD, PhD, Fogarty International Center director, spoke of investing in research capacity in international locations, adding that as a result, the U.S. is extending the reach of American science, innovation and health diplomacy. **Steven Blount, MD, MPH**, Centers for Disease Control and Prevention Office of Global Health director, echoed these points and called for attention to chronic disease through the world.



Roger Glass, MD, PhD



Steven Blount, MD, MPH

Look for notices from Research!America for you to weigh in on the importance of increased funding for global health research.

House Passes Genetic Nondiscrimination Legislation

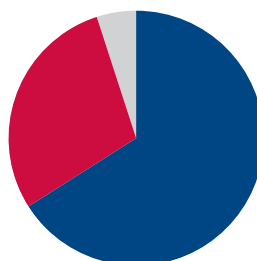
On April 25, the House of Representatives approved the **Genetic Information Nondiscrimination Act (H.R. 493)** with overwhelming bipartisan support, 420-3. GINA is designed to protect Americans from genetic discrimination by employers and insurers.

Passage by the House was a breakthrough because genetic nondiscrimination legislation was first introduced 12 years ago, but House leadership blocked it from coming to a vote until now. The Senate unanimously approved versions of GINA in 2003 and 2005, and easy passage is expected again soon. **President Bush** has indicated he will support GINA.

AMERICA Speaks

In order for scientists to study the differences that cause disease, they need to compare many individuals' genetic information. Would you be willing to donate genetic material such as a saliva or blood sample for this purpose?

Americans Willing to Donate Genetic Material for Research



Yes	66%
No	29%
Don't know	5%

SOURCE: YOUR CANDIDATES—YOUR HEALTH SURVEY, 2006
CHARLTON RESEARCH COMPANY FOR RESEARCH!AMERICA

Research!America Honored with ASBMB's Schachman Award

During the American Society for Biochemistry and Molecular Biology's annual meeting, Research!America President **Mary Woolley** accepted the Howard K. Schachman Public Service Award on behalf of the organization.

The award recognizes those who best demonstrate dedication to public service in support of biomedical science, as exemplified by **Howard K. Schachman, PhD**, chair of ASBMB's Public Affairs Advisory Committee for more than 10 years.

The ASBMB meeting was part of the larger **Experimental Biology 2007** meeting, which drew more than 12,000 biological and biomedical scientists.



Howard K. Schachman, PhD; Mary Woolley; William Brinkley, PhD

NIH Director Elias Zerhouni, MD, and **The Hon. John Edward Porter**, Research!America chair, presented "NIH at the Crossroads: How Diminished Funds Will Impact Biomedical Research and What Scientists Can Do About It."

Research!America's **Stacie Propst, PhD**, presented "How to Communicate with Congress About Research."

AAP Presidential Address Focuses on Education, Advocacy

Research!America board member **Dennis A. Ausiello, MD**, delivered his presidential address to the **Association of American Physicians** in Chicago on April 14.

The Hon. John Edward Porter, Research!America chair, spoke at the AAP annual meeting, reminding the audience of the importance of advocacy for research.

Anthony S. Fauci, MD, director of the **National Institutes of Allergy and Infectious Diseases**, was awarded the 2007 George M. Kober Medal of the AAP for his contributions to academic medicine. Fauci is a former AAP president.

Lymphatic Research Advocacy Honored

Six advocates for lymphatic research were honored by the **Lymphatic Research Foundation**, a Research!America member, at its Inaugural Awards Gala on May 10.

Wendy Chaite, Esq., a Research!America emeritus director, founded LRF. In a video that debuted at the gala, Research!America's **Mary Woolley** praised the foundation for its research funding advocacy.

See www.lymphaticresearch.org.

Did You Know?

Continued from page 6

R. Bruce Donoff, DMD, MD, dean of Harvard University's School of Dental Medicine, was elected president of **Friends of the National Institute of Dental and Craniofacial Research**, a Research!America member.

U.S. Department of Health and Human Services **Secretary Michael Leavitt** recently appointed six new members to the **Agency for Healthcare Research and Quality National Advisory Council**. See www.ahrq.gov/about/council.htm for a list of members.

Robert Kolodner has been chosen to head the U.S. Department of Health and Human Services **Office of the National Coordinator for Health Information Technology**. Kolodner had served as interim coordinator since September.

Research!America emeritus director, **M. Roy Schwarz, MD**, was awarded an honorary doctorate of humane letters from **Johns Hopkins University** at its May 17 commencement. Schwarz is former president of the **China Medical Board of New York**.

Sheilah Miller Satterwhite celebrated her 10th year of working for Research!America.

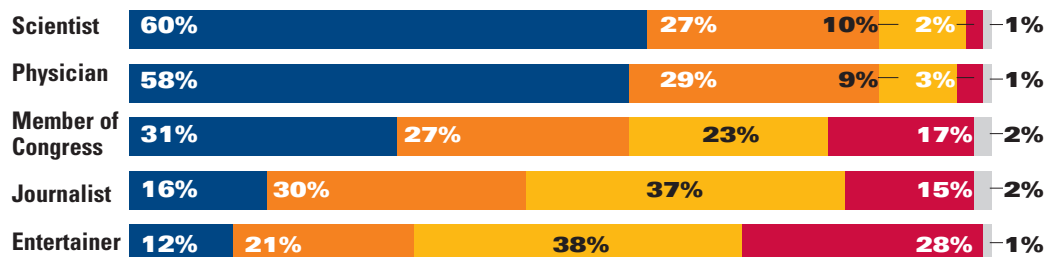
AMERICA Speaks

How prestigious do you feel each of the following is as an occupation?

SOURCE: BRIDGING THE SCIENCES SURVEY, 2006
CHARLTON RESEARCH COMPANY FOR RESEARCH!AMERICA

Scientist Most Prestigious Career

Very Great Considerable Some Hardly Any Don't know



ComingUp

June 2007— Find out where Congress stands on health and research! Survey responses from **Your Congress–Your Health**, a new initiative from Research!America, the Albert and Mary Lasker Foundation and other partners, will be online mid-month at www.yourcongressyourhealth.org

July 31, 2007—Deadline for nominations for **AcademyHealth's** health services research impact award. See www.academyhealth.org.

July 31, 2007—Deadline for Research!America's **Eugene Garfield Economic Impact of Medical and Health Research Award** nominations. Visit www.researchamerica.org/outreach/garfieldaward.html.

Are there others in your Research!America member organization who would like to receive our materials and information directly? Add them to our mailing lists today by contacting Kyndra Fuller at kfuller@researchamerica.org.

Advocacy & Action



**Your Congress.
Your Health.**

Engage Your Delegation in Your Congress–Your Health

As an advocate for health research, you are critical to the success of the **Your Congress–Your Health** initiative. All members of Congress recently received a 15-question survey on health care, research investment and other issues important to their constituents' health.

Please let your representative and senators know how important it is for them to go on the record on issues that are vital to our nation's health and prosperity.

Go to www.yourcongressyourhealth.org to urge your delegation to participate in **Your Congress–Your Health**.

Visit

US ON THE WEB www.researchamerica.org

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