

Making Medical Research a National Priority: The Work of Research! America

Mary Woolley, President, Research! America



"Doubling the NIH budget was not possible without Research! America."

### Recognition for Our Role

#### THE WALL STREET JOURNAL.

"The driving force behind the huge 15% increase in the NIH budget to \$15.6 billion was an umbrella organization called Research! America."

- Al Hunt The Wall Street Journal December 24, 1998



#### Influencing the Policy Agenda: 1999





A former Senator tells why he was wrong to neglect medical research funding.

## "I Had No Symptoms Of Heart Attack..."

#### By Paul Simon

S I LOOK BACK ON MY 22 YEARS IN THE heart arteries. The device takes a type of picture of the Presbyterian-St. Luke's Medical Center in Chicago on House and Senate, I realize I would like to change a few of the votes I cast. Most peopleand politicians probably more than most-hate to admit they are wrong. I was wrong though, and that was brought home to me recently in a most dramatic way. It started when I happened to read a magazine article on a new device for measuring blockage of the

heart and coronary arteries (called a "heart scan," something like an X-ray) that can pick up hidden problems. I had no symptoms of heart trouble, such as chest pain or shortness of breath, but the article noted that about 20 percent of those over 60 (I am 70) who have a heart attack or stroke have no advance warnings.

I set up an appointment for a heart scan at Rush-

Nov. 10 last year. The scan took 10 minutes, but the results were startling: I was headed for a heart attack or

stroke. As a result, last Jan. 5 I had a six-way heart bypass operation.

Today, I'm doing fine. It turns out that the heart scan-developed as a result of research

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ng I devot- discovered the benefits of medical research firsthand.

served in the Congress. I felt other issues

were more important. Now I know how wrong I was. All around me are others-former colleagues and

"Two-thirds of Americans agree that funding for medical research should be doubled, according to a poll taken last year by the nonprofit advocacy group Research! America."

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PARADE Magazine is the most widely read weekly magazine in the U.S., with a circulation of over 75 million.



"As a member of the U.S. Senate, it is incumbent upon me to hear the public voice about important issues.

Research! America, through its national surveys, gives me added evidence of the importance of medical and health research to our citizenry."



#### Research! America's Mission

Make research to improve health a higher national priority



# Research! America: 21 Years of Putting Research on the Public Agenda

- Non-profit alliance with member organizations drawn from academia, business, patient organizations and scientific societies representing more than 125 million Americans
- Distinguished, all-volunteer board includes former elected and appointed officials, media and public relations leaders, and leaders from alliance member organizations



# Research! America's International Affiliates

#### Research Australia

An alliance for discoveries in health

Founded: 2000

Mission: To make health and medical research a higher national priority.

#### Research Canada An Alliance for Health Discovery

Founded: 2005, evolved from the Council for Health Research in Canada (CHRC) into a broad-based alliance dedicated to collaborative advocacy action that builds support nationwide.

Mission: To help Canadians maintain and improve their health by ensuring Canada is a world leader in health research.



### Distinguished Board Includes:

- Former members of Congress and high-level Administration officials
- Leaders of academic and industry research
- Public health leaders
- Leaders of voluntary health organizations
- Major media personalities
- Venture capitalists
- Top advertising and public relations executives



#### What We Faced in 1989:

- "Preoccupation by Congress and the Administration with deficit reduction and competition for appropriations in a resource-scarce environment have resulted in woeful under funding of government agencies involved in medical research"
- from Research! America's Charter



- Set a very aggressive, quantifiable goal
- Assess the political environment
- Develop messages to support the goal
- Constantly test and demonstrate public support
- Employ earned and paid media
- Employ targeted lobbying when appropriate
- Track progress
- Be persistent
- Say "thank you"



#### First: A Definition

To advocate means to speak up, to plead the case of another or to champion a cause.

It is something that most of us routinely do on behalf of our families, our neighbors, our friends and ourselves.

Organized, persistent advocacy is the key to public policy change.



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## Set a Very Aggressive, Quantifiable Goal

#### POLICY FORUM IN AND ADDRESS OF THE PROPERTY OF THE POLICY FOR THE

#### Science and the New Administration

J. Michael Bishop, Marc Kirschner, Harold Varmus

With a new presidential Administration now in office, the scientific community is hopeful that measures will be taken to enhance research and the contributions it can make to our society. What little was said of research during the presidential company to the contribution of the community of th

The opportunities for progress through science are greater than ever. However, the last decade has witnessed an accelerating crossion of the infrastructure for fundamental research in the United Seates. If that crossion is not reversed soon the pace of discovery will necessarily decline, with widespread consequences for industry, health care, and education.

In hopes that President Clinton and Vice President Gore will soon address the proppects for basic science in the United States, we offer our view of how fundamental research benefit our nation and what should be done to secure those benefits for the future. We speak here for biomedical research, our area of expertise, but believe that our remarks illustrate problems and opportunities found throughout science.

#### The Promise of Biomedical Research

Recent progress in biomedical research has brought an understanding of molecules, cells, and organisms for beyond anything anticipated a generation ago. The benefits of this progress include the makings of a revolution in preventive medicine; novel approaches to the diagnosis and treatment of cancer, heart stracks, infections, inherited diseases, and other allments, the prospect of improving agricultural productivity in ways never imagined by the Green Revolution; new tools for environmental protection; and a renewed impetus to atimulate and inform public interest in science.

The economic benefits of these gains are substantial. Consider two examples: First, it is often argued that advances in research increase the costs of health care. However, biomedical research typically generates sim-

The authors are on the faculty of the School of Medcine at the University of California, San Francisco, and are members of the Joint Steering Committee for Public Policy. pler and less costly devices: Inexpensive viral vaccines now save the United States billions of dollars annually; new tests for viruses have helped cleanse our blood supply, greatly reducing the economic losses from diseases that are spread by transfusion; and growth factors for blood cells are cutting the costs of caring for patients who receive bone marrow transplantation or chemotherapy for cancer. Second, fundamental research spawned the biotechnology industry, of which our nation is the undisputed leader. Biotechnology is a growing contributor to our economy, a source of diverse and gratifying employment, a stimulus to allied industries that produce the materials required for molecular research and development (R&D), and a vigorous partner to our academic institutions in the

#### Challenges to Biomedical Research

Despite the progress, preeminence, and promise of American biomedical research, the enterprise is threatened by inadequate funding of research and its infrastructure, flawed governmental ovenight of science, confusion about the goals of federally supported research, and deficiencies in science education.

The productivity of biomedical research is limited most immediately by financial resources. In 1992 the nation spent about \$10 billion on biomedical research, mostly by congressional appropriations to the Na-tional Institutes of Health (NIH). This investment is too small by several measures: (i) The United States currently devotes between \$600 and \$800 billion annually to health care, yet less than 2% is reinvested in the study of disease. In contrast, the defense industry spends about 15% of its budget on research. (ii) U.S. expenditures on R&D as a percentage of our gross national product have been declining steadily and are now lower than those of Japan and Germany. Moreover, 60% of our R&D dollars is designated for defense. (iii) The funding of approved NIH grant applications has fallen below 15% in some categories and under 25% in many, compared with rates of 30% or more in the preceding two decades, when progress was so rapid. Under these conditions, outstanding proposals cannot be pursued, first-rate investigators have become dispirited, and even the best students are discouraged from pursuing a career in science. (iv) Outstanding institu tions lack funds for laboratories and re-

placement of itadequate instruments; as a result, the conduct of biomedical research is constrained and even dangerous.

Biomedical research is also impeded by outmoded procedures for the federal administration of science. Agencies that should be working together to promote research in the life sciences instead remain separated in competing departments. NIH has suffered from a chain of command that requires approval from secretaries and undersecretaries with little expertise or interest in science. Some sources of funding for remechanisms or expertise for initiating, judging, and administering programs, and others have not adapted their mechanisms appropriately to the progress that has been made in research. For example, many of the NIH study sections, traditionally the pride of the peer-review system, are now organized according to outmoded or otherwise inappropriate categories. In addition, the government has not learned how to involve the scientific community adequately in administrative decisions to initiate targeted projects. To cope with a decaying infrastructure, Congress has occasionally approeisted substantial funds for construction. but they have done so in a way that circumvents peer review and serves local needs rather than the advancement of science as a

The confidence that the scientific community once had in the federal governance of biomedical research has been further eroded by the use of inappropriate criteria for appointments to high-nanking positions, particularly within the Department of Health and Human Services. In recent administrations, it has become commonplace to consider political views on issues such as abortion and the use of fetal tissue in research. This tendency has compromised our ability to select leaders on the basis of their scientific accomplishments and their capacity to manage complex proserms and make objective decisions.

These administrative problems have been compounded by confusion over the goals of federally supported biomedical research. Economic woes have encouraged calls for increased application of current knowledge to practical problems in all branches of science. These appeals have special resonance in biomedical science now that so many opportunities for practical applications are at hand. In recent months, such calls for applied science have gained further prominence because they have been championed by National Science Foundation (NSF) director Walter Massey and Representative George Brown (D-CA), a long-time friend of science (1).

Claims that "society needs to negotiate a new contract with the scientific community

# Respected Researchers Made the Case

"...we recommend increasing the NIH budget by 15% per year, which would double the budget in current dollars by 1998."

J. Michael Bishop, Marc Kirschner,
 Harold Varmus
 Science. January 22, 1993



"[The goal] has to feel like history.
Incrementalism leaves the audience in a snooze."

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- Say "thank you"



# Barriers to Achieving the Doubling Goal, Mid-1990s:

- U.S. economy struggling
- Presidents George H.W. Bush and Bill Clinton not vocal champions for NIH
- Handful of Congressional champions
- Members of Congress and American public unfamiliar with NIH
- Stakeholders focused on disease-specific advocacy
- Researchers resistant to public engagement



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# Develop Messages to Support the Goal

 Less than a nickel of every health care dollar in the U.S. is being spent on medical and

health research





# Develop Messages to Support the Goal



## **Local Always Matters**

"All politics is local." —
 Thomas Phillip "Tip" O'Neill,
 Speaker of the House, 1977-87



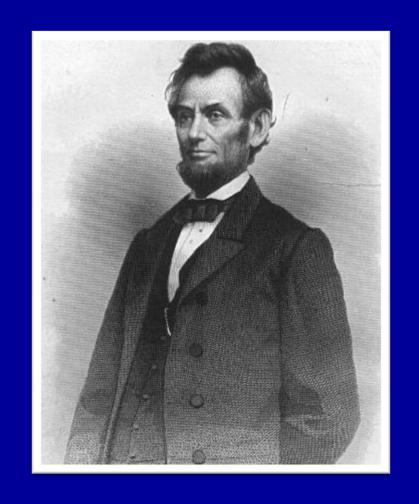
Local media is crucial:

San Jose Mercury-News, Stevens Point (WI) Journal, Anchorage Daily News, Iowa City Press-Citizen, Gainesville (FL) Sun, WWL-AM, WCAX-TV, Dayton (OH) Daily News, KTVB-TV, The Idaho Statesman, Omaha World Herald, The Oregonian, Topeka (KS) Capital-Journal, St. Louis Post-Dispatch



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"...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed."

## Poll Methodology

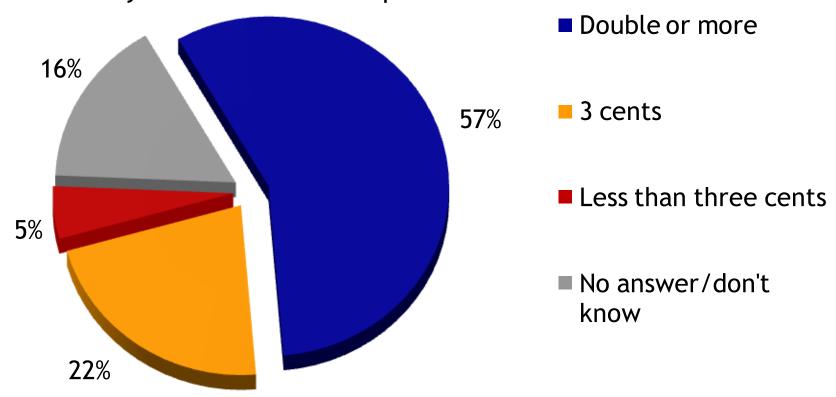
# Typical of general media and political polling:

- Telephone poll by random-digit dialing
- Size: 1,000+ adults aged 18 and over
- Theoretical sampling error: +/- 3.0%



# 1996: Public Opinion Lends Support to Doubling Concept

Currently, about 3 cents of each health care dollar spent in the U.S. goes for medical research. How many cents out of each health care dollar do you think we should spend on medical research?

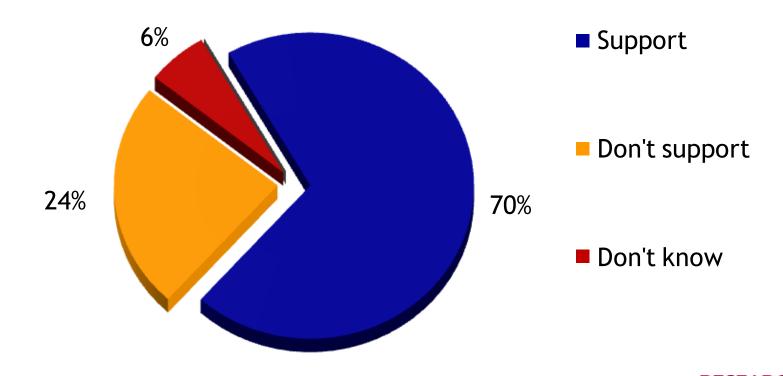


Source: Aggregate, 1996

Charlton Research Company for Research! America

## 2001: Support for Doubling Strong

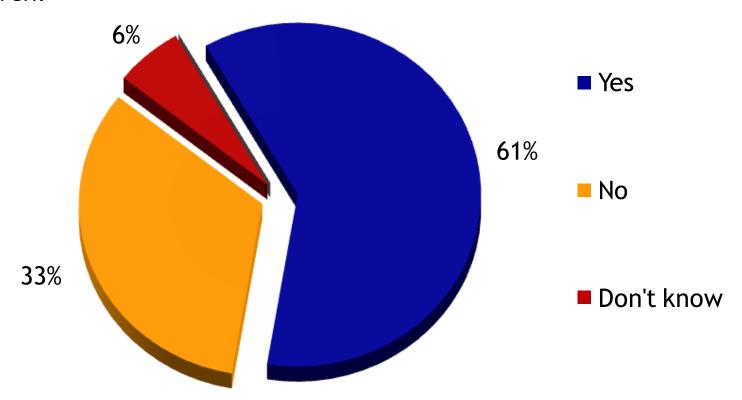
Do you support or oppose a proposal to double total national spending on government-sponsored medical research over five years?





# 1999: Public is Willing to Pay More in Taxes

Would you be willing to pay \$1 per week more in taxes for more health research?





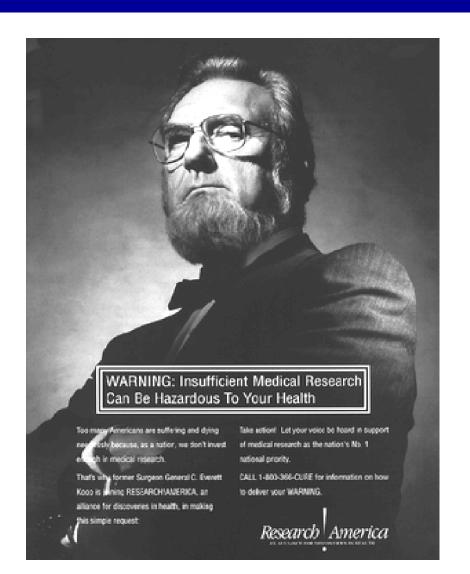
Charlton Research Company for Research! America



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# Earned Media: Public Service Advertisements





#### **Earned Media 1999-2002**

- Patient stories
- Op-eds
- Letters to the editor



THE WALL STREET JOHNSVAL THURSDAY, MAY IS, 2000

#### Who Will Take Their Place?

Short of the published community to worried about whe's coming to the next Congreen. Sunned Thier and Fuel Report are worsted about whe's learning.

Be. Then, president of Partners Healthcare, the organization that runs both the practiginary Managements General and ariginary dust Veinner's projects, and former Bey. Paul Ropers, chair of Reproveds America, are stought advected in Indertility Tanded health resource and the nation's teaching hospitals. The of their

Politice & Poople By Albert E. Hun

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by Mr. Regent to accountly double NELL funding over the years. Despite a lock of support from the Clinica infratelyimites, a hiparition confident of Inventions weerected to this past. The NEL budget man stands or UTA Miller and will elimb to ST Miller in several years.

"What we have been white to do." Mr. Porter noise, "It build broad support and conformating that there has a much good actions and those that the sunsh good sedence not these that even this budget work that anywhere mean all the good projects." That support and understanding. Mr. Begers notes, "would have been very difficult without Asian twitter..., is that seem the multip poroun to this effort," trans much growy as the mean agent some achievement of this Call? Congress, as furting for. Outside Book of Flerich also has played a major role. Set emaningly, Populationals have view fifthe in others regulate.

Research rearily produces quick results, or the real payoffs are yearn away. But almost every expect agrees that progress.

"Mr. Porter thinks one of the next

priorities should be a comparable

doubling of funding for public health

projects administered by the Centers

for Disease Control and Prevention."

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Mr. Moyethers have best to right more of a resegrand action to protect maching havpiteds. American has 120 developing medical centers—including Johns Buckens, Masses channels General, Dubeaud the University of Pennsylvania, the meet provide a centers in the world—and more than 400 mather large broyling.

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The results have been Darrosating; beyoffs, estimate and consolidation. The Deberative of Pensylvania. Empiral, considered to be one of the times over medicine in the constitution in the constitution.



John Porter

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### **Earned Media 1999-2002**

**December 30, 2002** 

#### **HoustonChronicle**

A PLEA TO CONGRESS

#### Save lives, free hostage research funds

#### By DR. MICHAEL DeBAKEY

S I write this, researchers are engaged in extraordinary research. They are taking skin, muscle and blood cells from heart patients, engineering them in a laboratory and injecting them back into those patients. The hope is that the engineered cells will transform into heart cells to make failing hearts pump more strongly and extend the lives of patients who would otherwise how to undown risks.



DeBakey is chancellor emeritus at the Baylor College of Medicine.

The ultimate goal: Many Americans no longer need be told by their doctors, "There is nothing more we can do."

Thanks to the NIH budget-doubling, so far we are on track to do the following:

■ Hasten research that takes cells from the inner lining of blood vessels to form a stent that the body will not reject. The stent aims to

Research! America has surveyed Americans from many walks of life. The results are stunning. In terms of national priorities, almost all Americans want more money for medical and health research. A striking 88 percent of Americans want the US to remain a world leader in medical research and feel more favorably towards candidates who support increased funding for research to find treatments and cures for disease.



## Earned Media, 1999-2002



Wednesday, March 28, 2001

#### Urgent need for scientific research

USA TODAY's recent article on the National Institutes of Health (NIH) warrants a response ("Medical research has healthy budget; Physics, astronomy may be casualties," Life, March 20).

The national commitment to the NIH should set the standard.

It's past time for Congress and the Bush administration to understand that a better future requires all kinds of scientific research.

While maintaining a commitment to doubling the budget of NIH, "a rising tide should raise all boats." For progress in health, we cannot afford to leave the physical sciences, mathematics and engineering in dry dock.

Mary Woolley, president Research! America Alexandria, Va.

## The New Hork Times

#### The Washington Times

THE TAMPA TRIBUNE
December 28, 1999





#### Paid Media





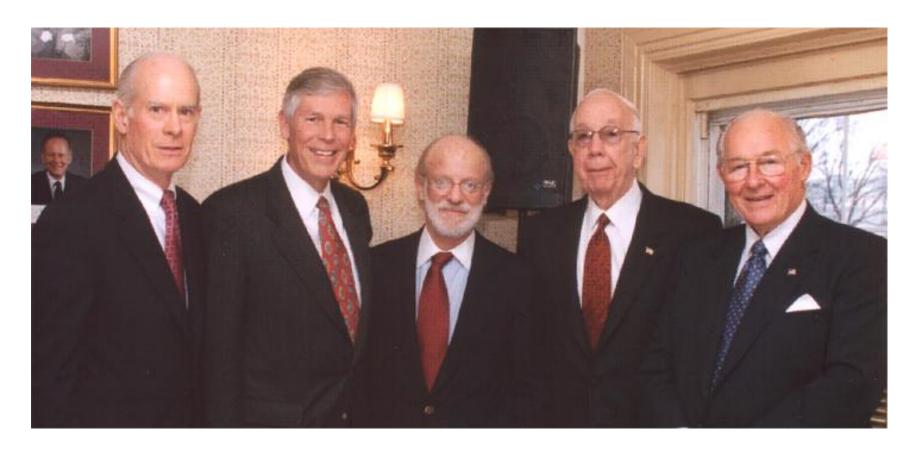




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## **Employ Targeted Lobbying**



Campaign for Medical Research: Hon. John Edward Porter, Hon. Connie Mack, John Whitehead, Hon. Paul G. Rogers, Hon. Bob Michel



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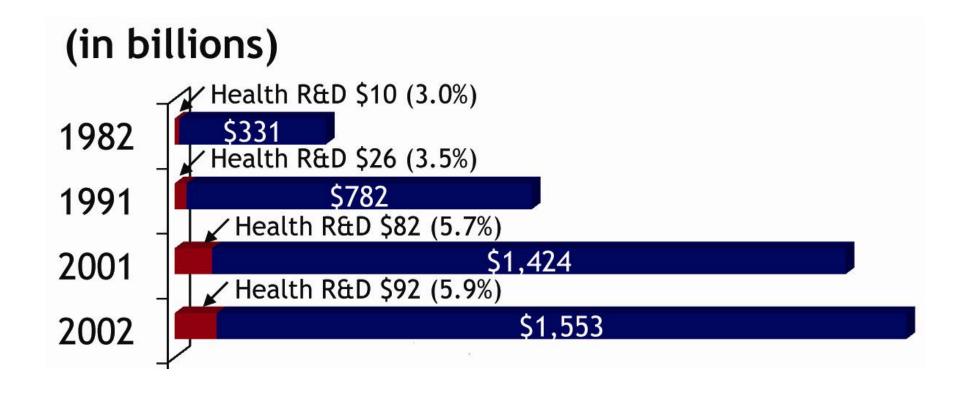


# History of NIH Doubling

1998	\$13.6 Billion	
1999	\$15.6 Billion	14.7% 🕇
2000	\$17.8 Billion	14.1% 🕇
2001	\$20.3 Billion	14.0% ↑
2002	\$23.6 Billion	15.8% 🕇
2003	\$27.2 Billion	15.3% ↑



# Health R&D as a Percentage of Total Health Costs





### Elements of Success: 1992-2002 Campaign to Double the NIH Budget

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"Too many voters have not made the connection between science and prosperity. Scientists need to tell the story. It has to be told and it has to be sold. Tell the story with data, tell it with anecdotes and tell it often."



"Perpetual optimism is a force multiplier."

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# Say "Thank You"





# Say "Thank You"

Research! America's Advocacy Awards dinner has been held annually since 1996 and has honored politicians, celebrities and organizations for their advocacy efforts.





# American Recovery and Reinvestment Act

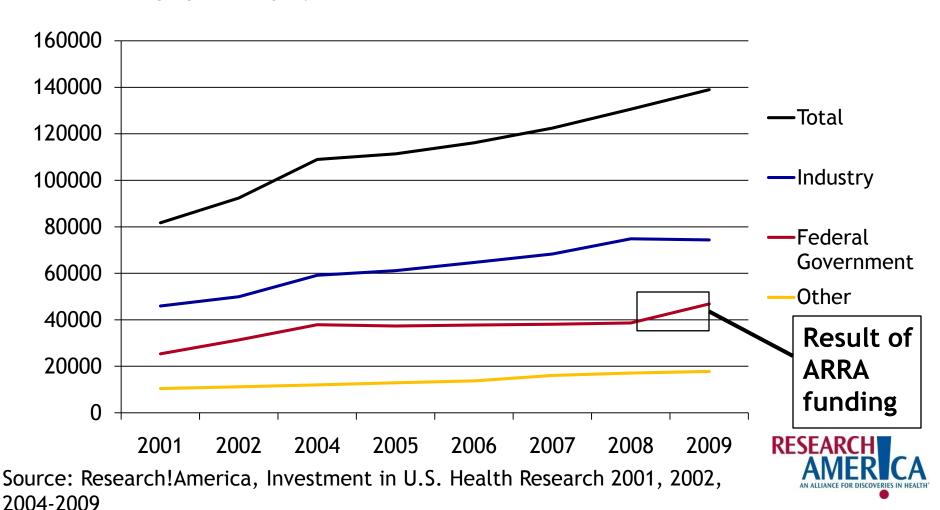
 Research! America led advocacy for 2009 ARRA (stimulus) funding for federal research agencies which included \$10 billion in funding for the National Institutes of Health in 2009





### U.S. Investment in Health R&D

#### Tracking Spending by Sector

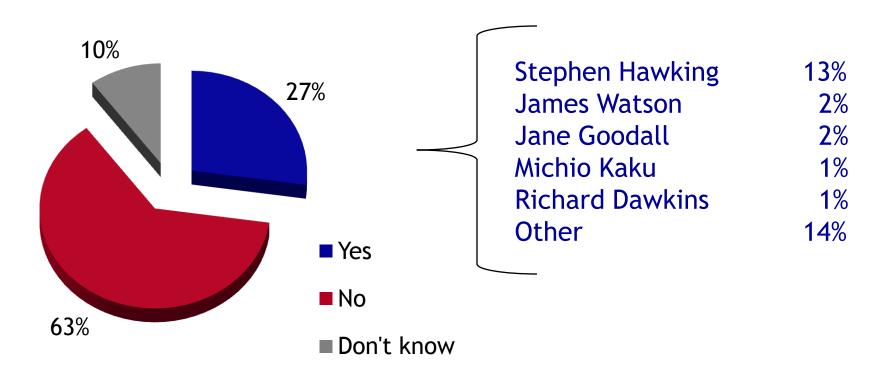


# Current Challenges



# Most Americans Can't Name a Living Scientist

Can you name any living scientists? (% total volunteered responses)

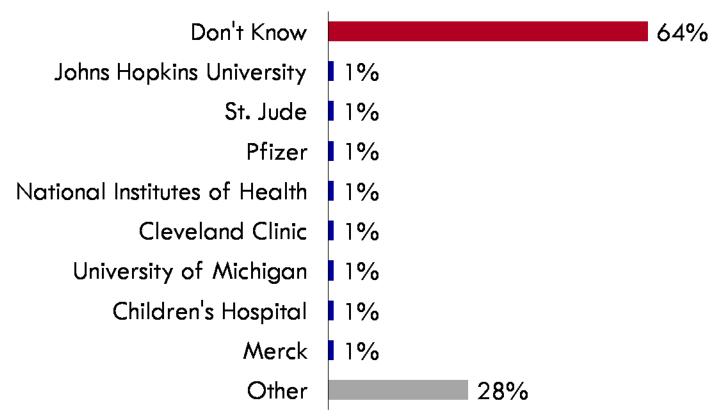


Source: National Poll, May 2010 Charlton Research Company for Research! America



# Americans Don't Know Where Research is Conducted

Do you know of any institutions, companies or organizations where medical or health research is conducted?

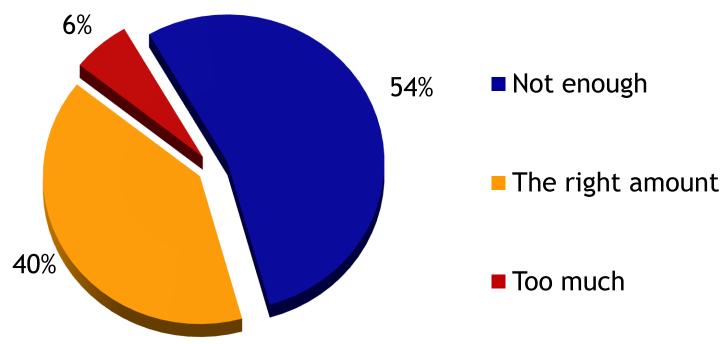


Source: Your Congress-Your Health Survey, May 2007 Charlton Research Company for Research! America



# U.S. is Not Spending Enough on Research

The U.S. spends 5 and a half cents of each health dollar on research to prevent, cure and treat disease and disability. Do you think that is too much, the right amount or not enough?

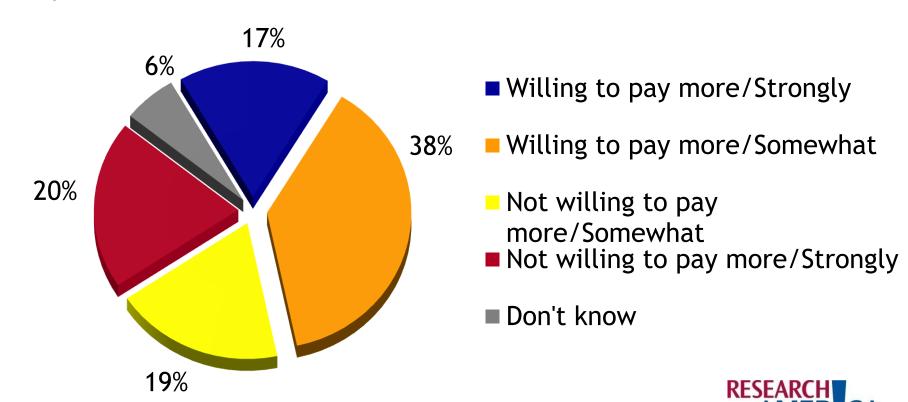


Source: National Poll, May 2010 Charlton Research Company for Research! America



# Americans Willing to Pay More for Research to Improve Health

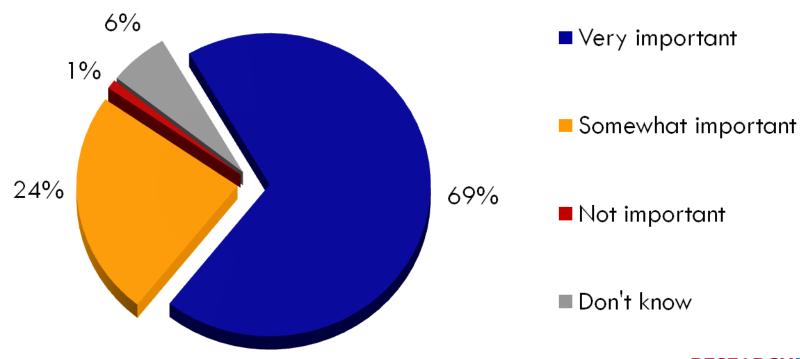
Would you be willing to pay \$1 per week more in taxes if you were certain that all the money would be spent for additional research to improve health, or not?



Source: National Poll, May 2010 Charlton Research Company for Research!America

# U.S. Should be a Global Leader in Research

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

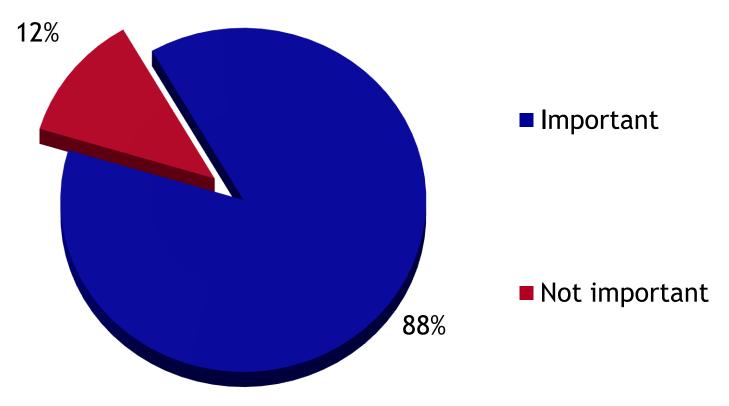


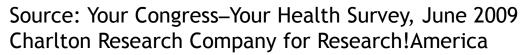
Source: Research Enterprise Poll, February 2010 Charlton Research Company for Research! America



# Scientific Research is Important for Job Creation & Incomes

In terms of job creation and higher incomes, how important do you think it is to invest in scientific research?

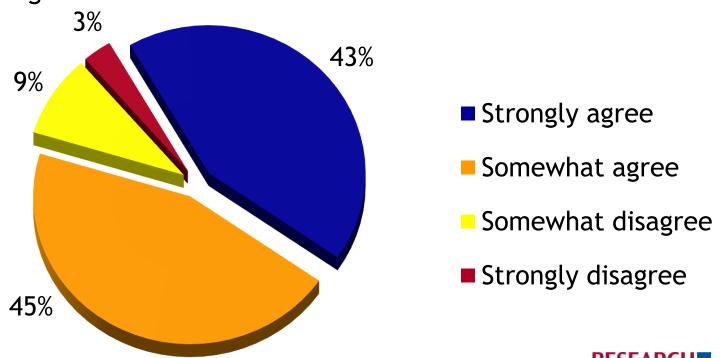






# Most Agree That Basic Research is Necessary

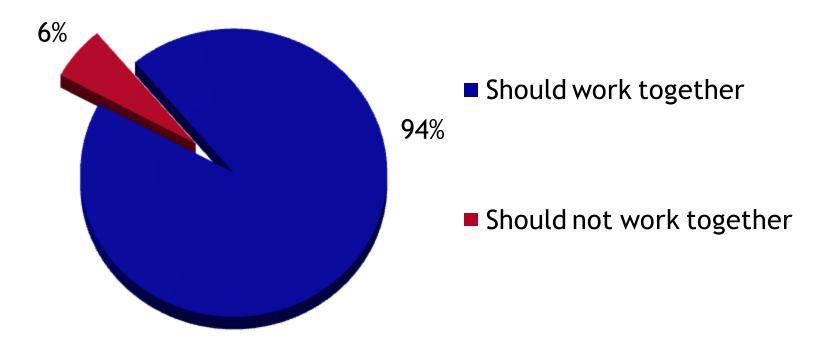
Do you agree or disagree with the following statement? "Even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government."



Source: Your Candidates - Your Health Poll, August 2010 Charlton Research Company for Research! America

# Research Institutions Should Work Together

Do you think the institutions conducting medical and health research in this country, such as government, universities, and private industry, should work together to develop new treatments and cures, or not?

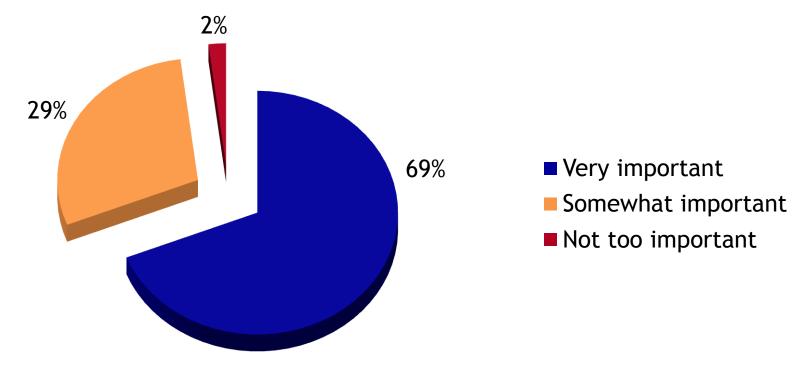


Source: Research Enterprise Poll, February 2010 Charlton Research Company for Research! America



# Americans Think Research is Very Important to U.S. Economy

How important do you think research is to the U.S. economy? Is it very important, somewhat important, not too important, or not at all important?



Source: National Poll, May 2010 Charlton Research Company for Research!America



### What Research! America is Doing

- Driving breakthrough advocacy for
  - Research as critical part of implementation of health care reform
  - Increased Research Appropriations
  - Embryonic Stem Cell Research
  - More Advantageous Tax and Regulatory Environment for Research
- Making the Economic Case
- Leading stakeholders in messaging and framing the case for research
- Building Champions
- Heightening Positive Media Attention to Research

### **Media Attention**

The New Hork Times

The Washington Post











- Policymakers respond to media
- Constituents learn from the media
- Media attention can create public pressure



### The New York Times

January 13, 2010

LETTERS

#### How to Stop America's Scientific Brain Drain

To the Editor:

The increase in foreign-born scientists who leave the United States to return home is the 21st-century equivalent of a Sputnik wake-up call and should galvanize American determination to maintain scientific leadership. Nothing less than our economy is at stake.

Some benefits of research quickly transcend borders, but economic impacts like new jobs and the resulting higher living standards mainly benefit the country of origin.

While United States spending on science was flat for years, others seized an opportunity. Japan, long the second-largest research and development spender, now trails China and India. How long until America's lead is overtaken, too?

Will we put America back on track to stay the world's leader in science and innovation, or let other nations reap the gains in jobs, growth and quality of life that once gave us such a source of pride and economic strength?

Mary Woolley President and Chief Executive Research!America Alexandria, Va., Jan. 7, 2010



# THE WASHINGTON SCENE

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Rep. David Obey (D-Wisc.) accepts the Edwin C. Whitehead Award for Medical Research Advocacy from Louis Stokes (left), Susan Whitehead (center), and Pharmaceutical Research and Manufacturer's Association CEO Billy Tauzin (right)



### Jobs and the Economy

- Economic Impact of Research: Jobs' impact of research money by state: www.researchamerica.org/state\_funding
- Growing the GDP
- Increase the percentage of GDP for research and development to 3%



### Percentage of GDP to R&D



Sweden spent 3.82% of its gross domestic product on research and development in 2007.

By comparison, the U.S. spent 2.62% of its GDP on research and development.

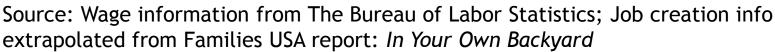


Source: 2009 Global R&D Funding report (published December 2008), Battelle

## Messaging: Research Creates Good Jobs

- In 2008, \$31 billion in government health research funding created and sustained 490,000 jobs.
- The average wage in the U.S. is \$40,000.
- The average wage for a life science worker in the U.S. is \$58,000.





## Garfield Economic Impact Award

Annually recognizes the outstanding work of one or more early-career economists that demonstrates how medical and health research impacts the economy

www.researchamerica.org/economicimpact\_award







"I believe the economic destiny of America lies in science, technology, innovation and research."

### **Effective Messages**

- Hope for the Cure
- Reducing the Cost of Health Care

e.g., treatments that delay the onset and progression of Alzheimer's disease by five years could save \$50 billion a year in health care costs; a one-month delay in admitting Alzheimer's patients to nursing homes could save \$1 billion a year





"Without research, there is no hope."

### Bringing Research Closer to Home

- "All politics is local"
- Media/Science Forums
- Advocacy Training Programs
- Editorial Board Visits
- Public-Opinion Polls
- Advocacy Tools for Scientists



# Scientists are the Strongest Voice for Science

- ... but don't speak out
  - "Though perhaps they are not well understood, scientists are highly respected in our society. They are also highly credible. When they speak with a unified voice, the people listen."
    - The Hon. John Edward Porter, Research! America Chair
  - Scientists are citizens and voters, too



### **Advocacy Tools for Scientists**

"The people we really listen to are voters. Not once have I heard anyone at a public meeting ask me, 'What are you doing for medical research?' Not even from a researcher!"

Rep. Mike Simpson (R-ID)

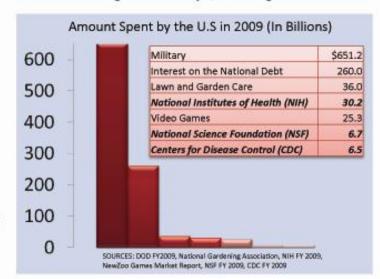


#### The Science of Advocacy

Advocating for research is as vital to advancing science as any discovery in the laboratory. Your voice is the strongest influence on how lawmakers and the general public views the importance of research. These pages demonstrate why it is crucial for you to become more engaged with policy makers and provide effective ways for you to engage the public and your representatives.

#### Funding Research Should Be a Higher Priority for Congress

- \$ The NIH budget is determined every year and no amount of funding is ever guaranteed
- \$ Because funding is an annual process, the need for research advocacy is constant
- \$ The Members of Congress that represent you should serve as your voice
- \$ There is no better representative of the research community than an actual researcher – you will be listened to and your opinion will matter



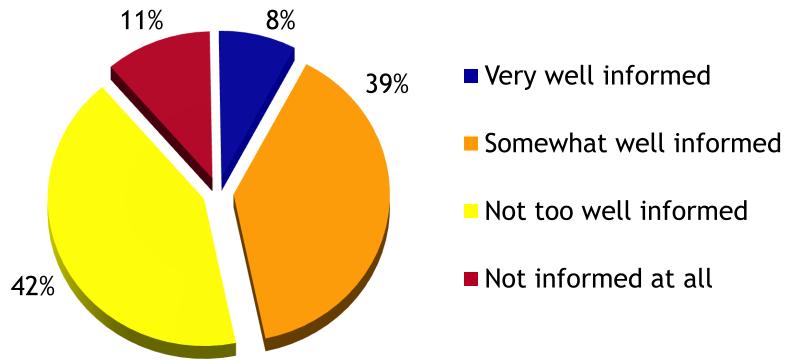




"The people we really listen to are the voters. Not once have I heard anyone at a public meeting ask me, 'what are you doing for medical research?' Not even from a researcher!"

# Most Not Well Informed on Elected Officials' Positions on Research

How well informed would you say you are about the positions of your Senators and Representative when it comes to their support of medical, health and scientific research?



Source: Your Candidates - Your Health Poll, August 2010 Charlton Research Company for Research! America



# Your Candidates-Your Health for 2010 U.S. Midterm Elections

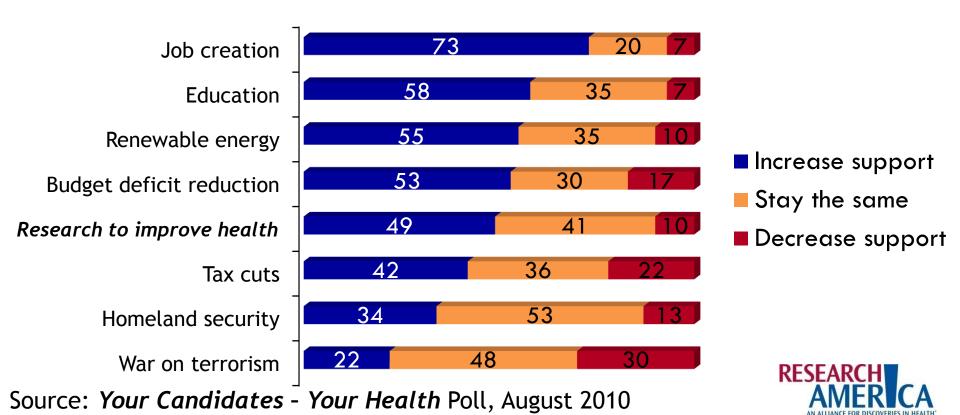


- Outreach to candidates
   Candidates for federal office have been invited to participate by providing
   responses to a questionnaire about health, research and related issues
- Extensive public outreach through the Research! America advocacy network and sponsoring partners to encourage candidates for federal office to share their views

www.yourcandidatesyourhealth.org

# Research Ranks Well with Other Top Election Priorities

Would you more likely vote for a candidate who supports increasing, decreasing or maintaining current federal spending on the following: (% response)



Charlton Research Company for Research! America



"NIH is spending \$95 per American this year on medical research, and we need to make every dollar count."

### Research Takes Cents

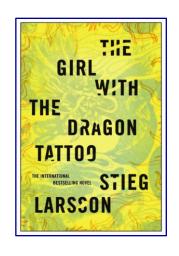


- Fast-food industry revenues reached \$120 billion in 2006.
- That would fund the National Institutes of Health for <u>more</u> than two and a half years!





### Research Takes Cents







 At 578 kronor each, this would fund nearly one-fourth of the Swedish Research Council's annual grants for research!



### Research! America: Ways to Connect

- www.researchamerica.org/blog
- www.researchamerica.org/facebook
- www.twitter.com/researchamerica
- www.youtube.com/researchamerica
- http://newvoicesforresearch.blogspot.com



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