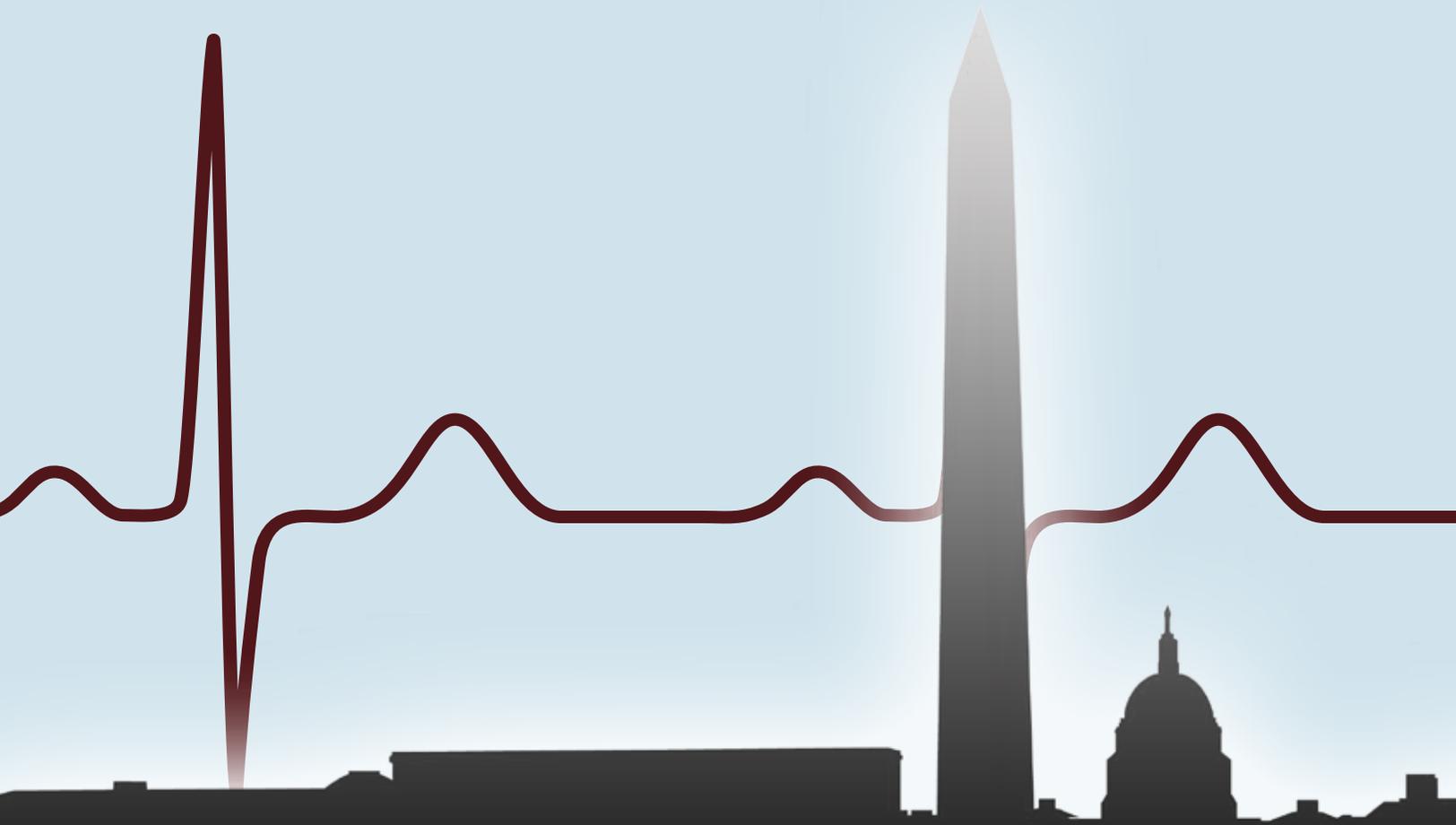


Profiles of Promise

MEMBERS OF CONGRESS FIGHTING FOR CURES



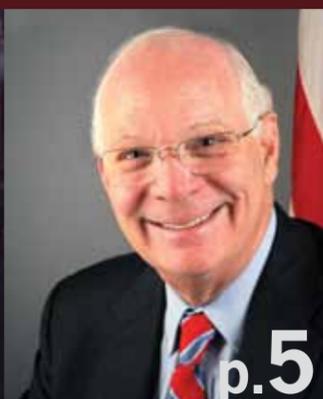
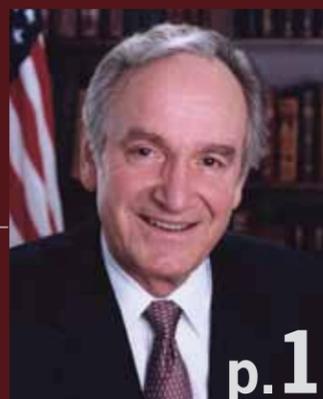
United for Medical Research

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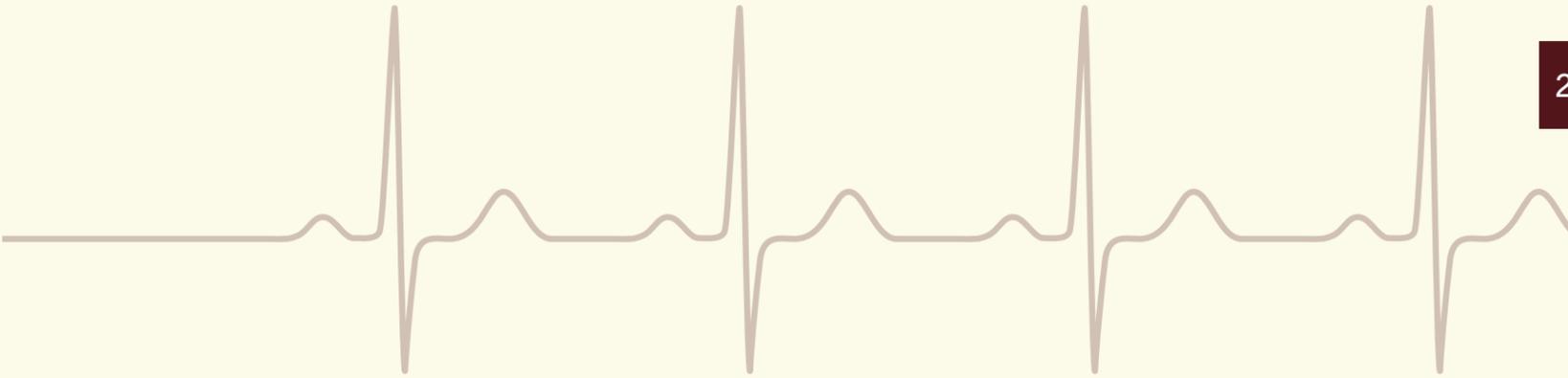
ADVOCATES FOR NIH

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FOREWORD by Senator Tom Harkin



Congressional appropriators are not supposed to play favorites among the programs under their jurisdiction, just as parents are not supposed to play favorites among their children. But, when it comes to National Institutes of Health, I long ago threw that rule out the window. As chair of the Appropriations subcommittee that funds health programs, and also as chair of the Committee on Health, Education, Labor, and Pensions, I am committed to doing everything in my power to maintain the leadership of this extraordinary institution.

NIH is the jewel in the crown of biomedical research not only in the United States but globally. More than 80 Nobel Prizes have been awarded for NIH-supported research. Five of those Nobels have been awarded to investigators in the NIH intramural programs for landmark discoveries that include the mapping of the human genome.

This is a dazzling record of discovery, and it has translated into countless lifesaving medicines, treatments, and therapies. Thanks significantly to NIH-sponsored research, deaths from heart disease are down 63 percent, and from stroke by 70 percent, since the 1970s. HIV is no longer a certain death sentence. NIH-sponsored research is the basis for the vast majority of new medicines — everything from cholesterol-lowering statins to pharmaceuticals that target specific cancers.

NIH is the jewel in the crown of biomedical research, not only in the United States, but globally. More than 80 Nobel Prizes have been awarded for NIH-supported research.

Today, the United States leads the world in biomedical research, in part thanks to generous funding for NIH and its research grant program. Senator Arlen Specter and I take pride in our success in doubling funding for NIH between 1998 and 2003. In February 2009, I was able to include a one-time supplemental infusion of \$10.4 billion for NIH in the Recovery Act.

But the years of abundant funding are now behind us. As I write this, the books on Fiscal Year 2011 still aren't closed. NIH is operating under a continuing resolution holding its funding at Fiscal Year 2010 levels. We face a significant challenge to gain a level of funding for the current fiscal year that, at a minimum, preserves NIH's purchasing power.

And new threats to NIH funding are on the horizon. The President's bipartisan deficit reduction commission offered its recommendations on December 1, 2010 — and commission members have made it clear that "everything is on the table." As the economy continues to recover, the federal government will be turning its attention away from stimulus and toward deficit reduction and cost-cutting.

While President Obama stressed the importance of investment in biomedical research in his 2011 State of the Union Address, it is going to be a huge fight to maintain NIH's relatively privileged status in the appropriations pecking order. Any reduction in after-inflation funding for NIH would be a grave mistake — a classic case of penny-wise, pound-foolish budgeting. I pledge to lead the opposition to any such cuts. It would be folly to starve NIH for funding at the very time when we are on the cusp of extraordinary breakthroughs in biomedical research.

Will we discover more effective targeted treatments for cancer, and possibly a cure? Will we invent medicines to prevent Alzheimer's disease, and a vaccine to prevent HIV-AIDS? Will we learn to restore sight? Will we learn to heal severed spinal cords, and make it possible for people in circumstances like those of the late Christopher Reeve to walk again? An affirmative answer to these questions depends on sustained, generous funding for NIH.

The fact is, unless basic research in the biomedical sciences is funded by the federal government, most of it will not get done. This basic research is not a luxury. Without the research of the past two or three decades, we wouldn't have many of the treatments and cures that we benefit from today.

On that score, I often note that we named this organization the National Institutes of Health, not the National Institutes of Basic Research. We must always remember that the ultimate goal of government-funded biomedical research is not just discovery for the sake of discovery, but discovery for the sake of better health and saving lives.

When I think of Dr. Francis Collins and all the other world-class scientists at NIH, as well as other researchers who receive NIH funding, I'm reminded of an old saying: "In times of great change, there are two kinds of leaders, those who usher out the old — and those are called pallbearers — and those who usher in the new — and those are called torchbearers."

Over the years, NIH-funded scientists have been among America's most ambitious and accomplished torchbearers. They have been wonderworkers, giving hope to tens of millions of Americans suffering from chronic disease or living with disability. I believe passionately that Congress has the responsibility to give NIH researchers the generous resources they need to continue their extraordinary work.

Fortunately, I do not stand alone. In the pages that follow in "Profiles of Promise," you will read the personal stories of key Members of Congress who have championed life-saving research at NIH. With the support of citizen activists all across America, we intend to ensure that the best days of NIH are in the future, not in the past.

Senator Tom Harkin (D-IA) chairs the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies and the Senate Health, Education, Labor and Pensions (HELP) Committee.

The fact is, unless basic research in the biomedical sciences is funded by the federal government, most of it will not get done. This basic research is not a luxury. Without the research of the past two or three decades, we wouldn't have many of the treatments and cures that we benefit from today.

The NIH is...

27 institutes and centers

with an annual budget of over **\$31 billion**,

funding nearly **6,000** in-house scientists,

50,000 competitive external grants, and

325,000 researchers at over

3,000 universities, medical schools and

other research institutions, in

every state and around the world,

which all adds up to ...an economic engine.*

* <http://www.nih.gov/about/budget.htm>

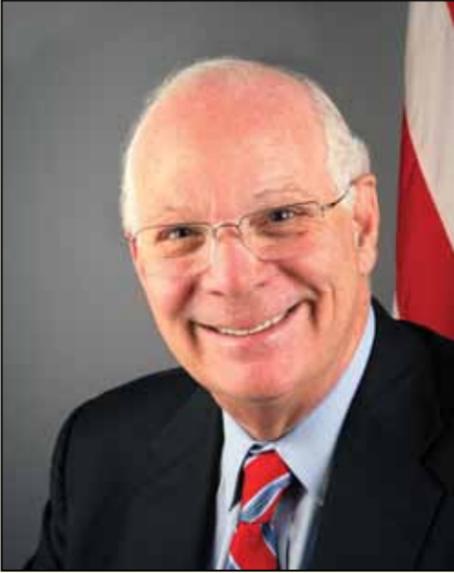


Mark O. Hatfield Clinical Research Center at NIH in Bethesda, MD.

PROFILES



Senator Benjamin L. Cardin



For Maryland Senator Ben Cardin, the benefits of the Bethesda-based National Institutes of Health (NIH) are very close to home.

“Clearly, America leads the world in medical research,” said Senator Cardin. “And if you have a rare or complex medical condition, you come to Maryland for treatment at NIH, or to one of the great academic medical centers in our state. Maryland is the epicenter for medical research.”

“The work at NIH is cutting edge,” he continued. “There, researchers are exploring ways to treat serious illnesses — cancer, diabetes, AIDS, mental illnesses. The answers we seek are being derived from the basic research at NIH.”

Approximately 10 percent of NIH’s budget supports projects conducted by nearly 6,000 scientists in its own laboratories, most of which are on the NIH campus in Bethesda, Maryland.¹ But it’s not just Maryland that sees the benefits of NIH. Currently more than 50,000 competitive research grants go to more than 325,000 researchers in every state and around the world to help further biomedical advancement, thanks to NIH.²

Senator Cardin supports biomedical research because it creates the foundation for the next generation of drugs and technologies to combat our nation’s health challenges. “The basic research funded by NIH is used by biotech and medical device firms to develop the therapies that improve the quality of life for millions of patients,” he said. Through two competitive grant programs — the Small Business Innovation Research (SBIR) and Small Technology Transfer Research (STTR) — a small percentage of NIH extramural research funds are directed to the nation’s small high-tech companies.

But Senator Cardin believes that discovering effective treatments and cures is only one benefit of NIH. He also sees the agency as an economic engine that spurs job creation through research positions and additional jobs that are necessary to support research and that come out of basic research discoveries.

“These are the types of well-paying jobs that American communities need. I’ve visited many of the biotech companies in Maryland; so many of them depend on the basic research performed at NIH. So this vital agency is not only developing treatments and cures, it’s also creating the jobs that help our economy.”

As a federal legislator for more than two decades, Senator Cardin is well aware of the impact that Congressional funding decisions have on the future of the world’s health.

“The support that Congress gives to medical research is critically important, not just for this nation, but also for the international community...”

In many cases, the work done here is partnered with other projects around the world, but the leadership comes from right here in America — from NIH.”

A native of Baltimore, Senator Cardin knows that the work of NIH has the potential to close profound gaps here at home that affect both the quality and cost of health care. “Health reform will change the direction of health care in America — getting everyone into the system, and bringing down the overall cost of care. But to improve quality, we must eliminate the health disparities in our nation.” Health disparities is a term that encompasses inequalities in health status — differences in health conditions and outcomes, and health care — differences in the services offered to people with similar conditions.

“Health disparities exact an enormous human and economic toll on our nation. Our nation’s overall health status clearly depends on our ability to improve the health of our fastest-growing communities and eliminate the disparities that are evidenced by higher rates of infant mortality and debilitating diseases such as heart disease, diabetes and cancer.”

Data from the U.S. Department of Health and Human Services’ Office of Minority Health confirms that African American children have a 60 percent higher prevalence of asthma than white children, Native Americans and Alaska Natives are 2.3 times as likely to have diabetes as whites, and Asian/Pacific Islander men and women have three times the incidence of liver and IBD cancer as whites.

“Some differences are attributable to lower rates of insurance coverage. Minorities — African Americans, Latinos, and Asians — constitute one-third of America’s population, but half of the uninsured,” Senator Cardin pointed out. “But even when you control for insurance coverage and income, studies have verified that minority patients receive lower-quality health care. This means that we must have a national strategy to close the gaps.

We need to know how we can best reach out to minority communities and address their needs. Unless you have a focus within NIH where basic research is done, we will not deal with it as effectively as we should. The good news is that with the passage of the Affordable Care Act, we have new tools to address disparities.”

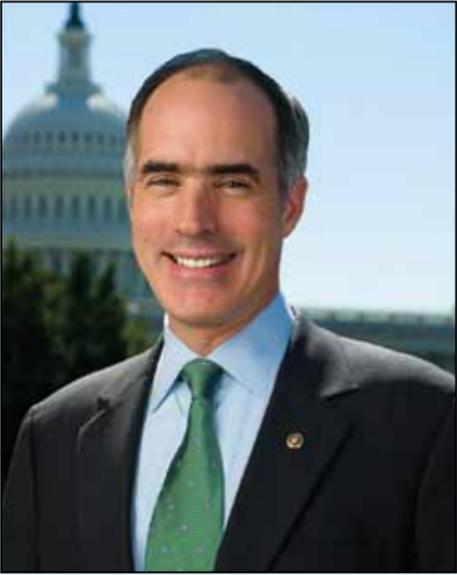
Senator Cardin authored a provision in the new health care law to establish Offices of Minority Health in six agencies of the Department of Health and Human Services and elevate the NIH’s National Center on Minority Health and Health Disparities (NCMHD) to an Institute. The new law clarifies the role of the new Institute Director as coordinator and manager of the NIH-wide minority health and health disparities portfolio, and provides the new Institute with professional judgment over NIH-wide minority health and health disparities budgets and funding. The new Institute will conduct and support research, training, and other programs including centers of excellence, research endowment and community based participatory research initiatives.

Senator Cardin believes that the new Institute is critically important so that “we can provide better quality services to all Americans, help bring down the overall cost of health care, and make this nation stronger.”

In summarizing his reasons for supporting NIH funding, Senator Cardin says, “It’s about maintaining our place as the leader in medical innovation; it’s about growing our economy and keeping the best-trained and best-educated scientists here in America. We have great academic medical centers and great biomedical companies. And NIH is the catalyst for creating the synergy of economic growth in our country.

“A vibrant NIH means a stronger economy and better lives for the people of this nation. It would be very short-sighted to cut back in an area that could mean real economic growth for America.”

Senator Bob Casey



Many years before becoming a Senator, Sen. Bob Casey Jr. was concerned about the health of his father, Bob Casey Sr., the 44th governor of Pennsylvania. Bob Casey Sr. had been diagnosed with amyloidosis, a rare genetic condition where proteins invade and destroy bodily organs.

“We were worried. We were scared. There was no cure for the disease. There is still no cure for the disease. But my father was undergoing treatment, and even after he had an organ transplant, there was rejection of the organ, and we weren’t sure he was going to survive,” said Sen. Casey.

But thanks to medicine that had been specifically designed, via research, to aid with transplantation rejection, Bob Casey, Sr. did survive and go on to complete his second term as governor.

“Because of the wonders of medical technology and all the benefits that we get from biomedical research, his life was saved,” said Sen. Casey.

“Biomedical research brings light where there’s real darkness in people’s lives because they think there’s no cure, no way to deal with the disease or a condition.”

Sen. Casey’s father benefited from biomedical research conducted at the University of Pittsburgh, which receives funds from the National Institutes of Health (NIH).

Sen. Casey believes NIH investment is crucial to medical research and the corresponding scientific advancements made in labs not just at the University of Pittsburgh, but across the country.

“Biomedical research brings light where there’s real darkness in peoples’ lives because they think there’s no cure, no way to deal with the disease or a condition,” said Sen. Casey. “And over time, because of the wonders of research and brainpower that Americans are so well known for, and our spirit of innovation, we’re able to use the research dollars that NIH spends every year to provide cures and treatments that even a few years earlier, may not have seemed possible.”

That’s why, even in a time of tough budget decisions, Sen. Casey believes it’s so critical to make investments in biomedical research and NIH.

“If you have a difficult federal budget and revenues are more difficult to come by, then that’s the time that you have to make sure that you don’t go off course,” he said.

For Sen. Casey, biomedical research is not just about the discoveries and cures; it’s also an economic engine that spurs job growth in Pennsylvania. He said, “There are not just a lot of jobs created [by research], but they are high-paying jobs. When we talk about the jobs of the future that we’re trying to create — the high-skilled, high-wage jobs that we want to create here instead of losing our edge — those are the jobs that are being created by biomedical research.”

Specifically in Pennsylvania, Sen. Casey believes there are far-reaching benefits of biomedical research, “at both ends of our state. Not just in Philadelphia and Pittsburgh, but a lot of places in between, where direct dollars go for research in universities and other research institutions where we’ve seen the benefits for the people of Pennsylvania.”

And just as biomedical research helps his state, Pennsylvania returns that investment by developing some of the nation’s top research projects in Alzheimer’s, Lou Gehrig’s Disease, HIV and many other diseases. According to Sen. Casey, “The research that gets done in Pennsylvania has affected the country and the world in a very positive way.”

If America doesn’t make the necessary investment in biomedical research, Sen. Casey feels that other countries will.

“You have a lot of emerging economies around the world. And unless we keep our edge and invest in education, invest in research and development, and especially in the biomedical area, we’re going to fall behind. We’ve got to make sure that we don’t lose that American edge that we’ve had for so long,” he said.

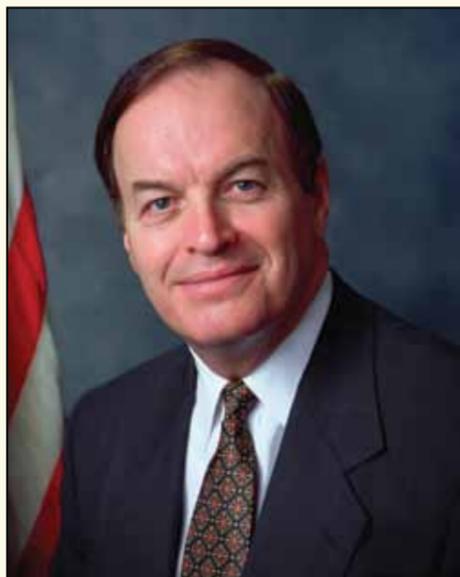
The payoff for a strong U.S. commitment to research, according to Sen. Casey, is that Americans all across the country will live longer, healthier, more productive lives.

“We as Americans have the important investments we make in education. We have that spirit of innovation. People who want not just to find a cure, but to be able to take it from the research setting out to the market so that Americans can benefit from that research directly.” Thanks to that American spirit of innovation that drives biomedical research and strengthens biomedical research funding, people everywhere are able to experience the tremendous service that the Casey family — both father and son — have done for the people of Pennsylvania.

As Sen. Casey said, “Biomedical research didn’t just benefit my father, it benefits the lives of fathers and mothers everywhere.”

“You have a lot of emerging economies around the world. And unless we keep our edge and invest in education, invest in research and development, and especially in the biomedical area, we’re going to fall behind.”

Senator Richard Shelby



When Senator Richard Shelby's wife, Dr. Annette Shelby, was stricken with kidney failure from lupus, he faced the same kind of powerlessness that families across the country feel when a loved one is confronted with a difficult disease.

"Twenty-three years ago, my wife had been treated for lupus for years, but her kidneys failed and we didn't know what to do. We thought she was lost. We thought she was gone."

Lupus is a chronic, autoimmune disease that can damage any part of the body, including skin, joints, and internal organs. Because the immune systems of lupus patients cannot tell the difference between healthy tissues and viruses, bacteria, germs and other foreign invaders, autoantibodies attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body, which can be debilitating and difficult to diagnose.³

Dr. Shelby had undergone treatment for lupus locally, but now believed that the best care for her kidney failure could be found at a medical research university rather than a

nearby hospital. To that end, Sen. Shelby reached out to the staff of the University of Alabama at Birmingham (UAB) to treat Annette.

"We knew where we lived probably didn't have the advanced capabilities necessary to deal with [such an intense treatment], so we turned to the University of Alabama at Birmingham," said Sen. Shelby. "They had the doctors and nurses with the research expertise and experience to treat my wife. They revived her, they saved her. That's when I realized what difference research hospitals can make."

If not for the medical research staff at the university hospital, Sen. Shelby believes his wife's treatment would not have been successful.

"This wouldn't have happened in an ordinary hospital. This was an extraordinary feat by the extraordinary medical team at UAB's teaching and research hospital," Sen. Shelby said.

Sen. Shelby considers this first brush with an Alabama research hospital as an entry point to a larger, national issue: federal funding of biomedical research conducted at universities across the country.

"I saw firsthand what [research hospitals] could do for my family, for my wife, and what they've probably done for thousands of others. When I realized what UAB did to save my wife's life at such an important time, I realized that they could save thousands of other people in my state of Alabama and across the nation, and also what cutting edge research teaching hospitals were doing nationwide. UAB is a lot like a lot of other teaching and research hospitals around the country," said Sen. Shelby.

"The future is bright, but the future must be funded."

"I believe that for every dollar we spend in biomedical research through NIH, through the states and through private organizations, we get a ten-fold return — and probably more than that. It's the beginning. It's catalyst for much more."

Since that day, Sen. Shelby has been a strong supporter of biomedical research, not just for personal reasons but for economic reasons as well. Sen. Shelby feels that biomedical research not only creates jobs, but also makes the U.S. a competitive force internationally.

"I think [research] puts us at the cutting edge of biomedical technology and spawns so many jobs, industries and companies that we can't even list them. And I think we're just scratching the surface. We've learned so much in the last 10 years, even five years, even two years. Where are we going to be in 10 years, or 15 years? And a lot will be because of biomedical research."

So how can we ensure that such scientific progress continues? Sen. Shelby believes "the future is bright, but the future must be funded." Specifically, this means funding the National Institutes of Health (NIH). He continued, "I don't think there's an option of not funding; it's what you fund and how you do it."

"I believe that for every dollar we spend in biomedical research through NIH, through the states and through private organizations, we get a ten-fold return — and probably more than that. It's the beginning. It's catalyst for much more. I think you will see much more of that in the future," Sen. Shelby explained.

These days, Annette Shelby is far from where she was 23 years ago. At a Lupus fundraiser in 2004, Dr. Shelby said, "I'm here tonight because of modern medicine, because of the support from my family, because of the grace of God." The experience of Sen. and Dr. Shelby is proof

that biomedical research is a crucial part of our future well-being.

As Sen. Shelby plainly stated, "I believe that the funding of NIH and biomedical research and everything that's auxiliary to that is not only an investment in our own people, our own families, our own communities — it's an investment in mankind. Period."



Senator Shelby stands with wife, Dr. Annette Shelby.

Representative Brian Bilbray



“We need to work together, Democrats, Republicans and Independents. We need to work as Americans.”

What heat? Rep. Bilbray has long upheld an equally strong commitment to fiscal conservatism — which means he usually advocates for less government spending, not more. But biomedical research is an exception. The federal government has the scale and ability — and, Rep. Bilbray believes, the constitutional obligation — to invest in the nation’s research foundations. With an annual budget of more than \$31 billion,⁴ NIH is truly able to spur the nation’s medical research enterprise. It’s from there that private investment and research institutions may help build tomorrow’s miracles.

“Some of us have to stand up and be willing to take the heat to do the right thing if we want to see the miracles in the future.”

The federal commitment must be also be sustained over long periods of time. Only sustained investment, says Rep. Bilbray, will allow future generations to live better. From 1998-2003, Congress doubled NIH’s budget.⁵ But at the end of that period, funding essentially flatlined and — apart from a one-time infusion of Recovery Act funding — has remained flatlined ever since.⁶ For this reason, Rep. Bilbray calls the doubling, in which he admits his strong involvement, “well intentioned,” but unsustainable over the longer-term.

It’s heartbreaking to lose a parent to disease. It’s devastating to lose a child. Representative Brian Bilbray has suffered both.

“I was in 10th grade when I lost my father to cancer. I watched what that hideous disease can do, not just to my father, but to the entire family.

“But I have to say that it was when I lost my first son to crib death, SIDS, that I received the biggest wakeup call about how important research is,” Rep. Bilbray said.

These experiences inspired Rep. Bilbray’s longstanding commitment to helping others avoid such tragedies by supporting federal government’s investment in biomedical research through the National Institutes of Health (NIH).

“Some of us have to stand up and be willing to take the heat to do the right thing if we want to see the miracles in the future,” he explained.

Instead, he says, the solution must be a collaborative, non-partisan effort to find a truly long-term, even generational, strategy for NIH that will encourage the entire biomedical ecosystem to thrive.

“We need to work together, Democrats, Republicans and Independents. We need to work as Americans to find the level of commitment that the federal government can make so that private investors and researchers can know that there is long-term involvement. And that in turn allows them to know what long-term commitments they need to make,” said Rep. Bilbray.

Additionally, Rep. Bilbray believes we must reform the federal government to ensure these research breakthroughs are translated to innovative, lifesaving products for our citizens. This includes reforming the Food and Drug Administration so that we can bridge the infamous “valley of death” and translate research from bench to bedside.

Those commitments are essential goals for Rep. Bilbray as a seasoned Congressman, but also as a son and father. There have been great strides in cancer treatment: the overall death rate has steadily declined since the early 1990s and the five-year survival rate is now 68 percent, up from 50 percent in the 1970s.⁷ And researchers know today that cancer isn’t just one disease, but hundreds which we must fight with precision at the molecular and genetic levels. That said, cancer is expected to take 569,490 American lives this year, just as it took Bilbray’s father.

“We’re talking about real lives, real people, and real opportunity to avoid future tragedies...so it’s not what you do in the next year or the next election. It’s what you’ve done by the time your grandchildren show up. That’s going to be the real test.”

And while significant studies have given parents strict guidelines on how to avoid SIDS, the leading cause of this fearsome disease remains a mystery.

In sum, much has been accomplished, but Rep. Bilbray believes there’s much more we can do.

“I worry that we take our modern miracles for granted, because this is something we must not do. Who would have thought in the ‘60s that our daughters could get a vaccine to avoid cervical cancer? There’s a lot of long-term investment and a lot of good science that makes these miracles possible. And that means if we want to see them in the future, we’ve got to be willing to do the research today.”

Doing the research starts with significant, sustained investments in the National Institutes of Health. Regardless of political views or economic schools of thought, Americans agree upon the need to continue investing in biomedical research. Because disease impacts every one of us — including the men and women in the U.S. Congress. For Rep. Bilbray, we have a clear call to take action for our collective future to ensure significant and sustained investments in NIH.

“It’s not an abstract. We’re talking about real lives, real people, and real opportunity to avoid future tragedies... so it’s not what you do in the next year or the next election. It’s what you’ve done by the time your grandchildren show up. That’s going to be the real test.”

Representative Rosa DeLauro



In March, Representative Rosa DeLauro will celebrate 25 years as an ovarian cancer survivor. She will reflect on her accidental — but lifesaving — diagnosis. She will look back at how she feels her life was returned to her. And perhaps most important, she will honor the 15,000 women every year who are unable to survive the deadly disease.⁸

“I’ve always viewed the NIH as a jewel in the crown of our biomedical research. It’s the foremost biomedical research organization in the world. Not just the United States.”

As Rep. DeLauro celebrates, she will also continue to work tirelessly to support biomedical research, including efforts to develop a reliable screening test for ovarian cancer because, as Rep. DeLauro says, “No one should be just diagnosed by luck.”

The key to conducting this research, and thousands of other research projects around the world, is the National Institutes of Health (NIH). Although NIH has more than 75 state-of-the-art laboratory facilities at its headquarters in Maryland, more than 80 percent of NIH-funded research activities are conducted by scientists working in every state and around the world.⁹

Rep. DeLauro said, “I’ve always viewed the NIH as a jewel in the crown of our biomedical research. It’s the foremost biomedical research organization in the world. Not just the United States. We are the cutting edge of research.”

“Simply put, I view that biomedical research saved my life,” she continued.

Shortly after her successful cancer treatment, Rep. DeLauro decided to run for her first term in Congress and pledged to work on the Labor, Health and Human Services Subcommittee, which handles NIH funding.

While in Congress, Rep. DeLauro has worked with other female biomedical research champions, such as Pat Schroeder, Connie Morella, Louise Slaughter, Nancy Johnson, Marge Roukema, Nancy Pelosi and Nita Lowey, to advocate both for women to be included in clinical trials and for the development of the Office of Research on Women’s Health at NIH.

“It’s not that long ago when women’s health was not front and center, no matter where, whether at the federal level or anywhere else. And it’s true that at NIH, the clinical trials did not include women and women of color. They extrapolated data from men to women. Well, physiologically women are different. It doesn’t take a rocket scientist to figure that out,” said Rep. DeLauro.

Rep. DeLauro also advocated for doubling the NIH budget from 1998-2003, but feels the effort didn’t go far enough. In order to succeed, Rep. DeLauro believes NIH needs a strong, sustained commitment to funding because research doesn’t happen overnight.

“No one’s intent had ever been that once we doubled it we would just leave it, because research takes a long time. But if you do not invest now, in 10 or 15 years you will not be the beneficiary of the new discoveries. Nor will you allow those new researchers, those young scientists, to be able to get those grants that they need in order to perform the science that will continue to be breakthrough,” she said.

These biomedical breakthroughs don’t just stop in the laboratory, but they also translate to better treatments in the form of specific medicines, high-quality equipment and sophisticated procedures.

As Rep. DeLauro said, “It’s not only transforming people’s lives, but in terms of how this country — and quite frankly the world — works to allay suffering, it’s the science-based effort which allows us to be able to translate research to drugs and procedures to save lives. They’re in the business to save lives.”

When her colleagues in Congress ask why they should fund biomedical research right now, with all of the other programs that also need funding, Rep. DeLauro’s answer is simple.

“What research is about is saving lives. Many other parts of the federal agencies or the government do all kinds of good things. We do roads. We do bridges. We do parks. We do loans and grants for education and for the environment. But this is an area where we save lives.

“There is a moral responsibility that we have to take on and that we need to do whatever we can to increase the opportunity for people to survive illnesses that they don’t bring on themselves. And every step and every dollar and every resource that we commit to the National Institutes of Health brings us closer to saving more lives.”

Rep. DeLauro’s career, and indeed her life itself, is living proof of that statement.



Rep DeLauro talks with students about the Breast Cancer Patient Protection Act.

“Every step and every dollar and every resource that we commit to the National Institutes of Health brings us closer to saving more lives.”

Representative Mike Honda



“It’s a real exciting time for our young people to really start to open up their own imaginations. But it’s not going to happen by accident. It has to be conscious and purposeful.”

On a busy afternoon at the Longworth House Office Building, Representative Mike Honda sat down between votes to talk about an issue near to his heart: biomedical research.

“Health and research has always been something of interest to me. I majored in biological sciences. My father wanted me to be a doctor. I fought that, because it was my father telling me to do it. So this is probably a gift back to my Dad, making sure that we are supporting the area of medical research and medical science,” Rep. Honda said.

Honda marveled about how far science has come since his days as a science teacher.

“Today we’ve gotten to the point where physical and biological sciences are coming together at the nano-scale. And that, to me, is probably one of the most exciting things that could happen,” he said. “I want to help foster this collaboration, which is why I reintroduced the Elevating Science Technology Engineering Mathematics Act in Congress this summer, to improve STEM education coordination and coherence among federal and state governments and to advance STEM education across the nation.”

In order to take further advantage of our nation’s transformative moment in science, Honda believes we need to invest in the National Institutes of Health (NIH). “[Science today] moves us into an arena that is going to be opening up all kinds of items,” he said. “In order to do that, you need to have research. You need to have a place where all of that research can be coordinated, or guided, or initiated from. NIH is one of those agencies that can do that.”

As Rep. Honda sees it, not only will investment aid in the continued success of research projects currently underway, but it will ensure that the next generation of biomedical researchers is ready at the helm.

“It’s a real exciting time for our young people to really start to open up their own imaginations. But it’s not going to happen by accident. It has to be conscious and purposeful,” said Rep. Honda.

One particular area of science that Rep. Honda feels needs to be studied further is Hepatitis B, a highly contagious virus that infects the liver. According to the Centers for Disease Control (CDC), Hepatitis B affects as many as two million Americans, half of whom are Asian Americans.¹⁰



Rep. Honda poses with staff and patients at the Gilroy Neighborhood Clinic in Santa Clara County.

While visiting patients in a Hepatitis C program, Honda discovered “that hepatitis has a whole bunch of alphabets to it,” including Hepatitis A and B. He learned of the disproportionate number of Asian Americans affected by Hepatitis B, the disease that the U.S. Department of Health and Human Services calls “one of the most serious but frequently neglected racial and ethnic health disparities in the U.S.”¹¹

Rep. Honda hopes that funding Hepatitis B research programs will lead to reduced health disparities. “The whole issue of diversity plays into it because we come with our own background and our own interest and our own stories,” he said. “And we — in my mind — we convert that into policy. And so the policy becomes more refined, more on point, more focused, and if you will, more elegant.”

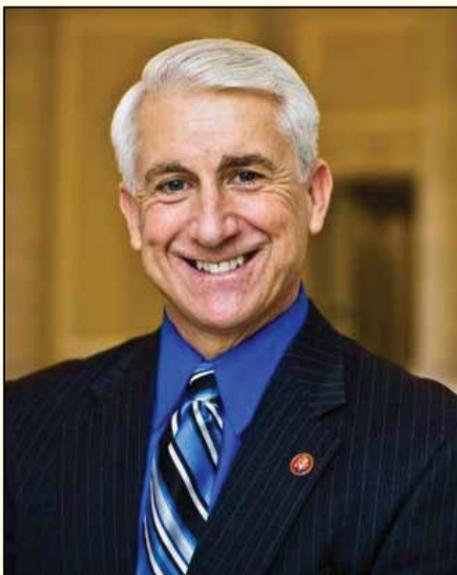
Highlighting that these diseases affect policymakers on both sides of the aisle, Honda said, “Viruses and bacteria, they don’t care what party you belong to. And they’re going to take advantage of whatever medium they find themselves in.”

He therefore stressed that policymakers must make strong, continuous investments in biomedical research, not just to help with the specific issues of medical disparities and Hepatitis B, but to help with the overall health and well-being of the nation and world.

“We have a responsibility to the entire country to utilize our resources and our genius for the betterment of mankind. And we have a global responsibility too. And so that allows doctors to be able to continue their Hippocratic oath — do no harm.”

Luckily, Rep. Honda is up for the task.

Representative Dave Reichert



Regrettably, every American has been touched by a loved one's disease. For Rep. Dave Reichert, disease has not just touched his life once, but has instead affected multiple family members and friends.

Nearly 14 years ago, his 18-month-old godson, Kyle (pictured to the right), was diagnosed with a rare cancer, and the toddler's parents were told their son wouldn't live for more than 2 years. Kyle has survived many painful treatments and medical procedures thanks to his strong will and positive attitude, as well as support from family, friends and teams of medical doctors and therapists. Rep. Reichert calls Kyle "a champion and a great inspiration to us all."

Two other inspirations in Rep. Reichert's life are his mother, who is a pancreatic cancer patient, and his former colleague, who lost his battle with Lou Gehrig's disease. It's no wonder, then, that these stories and experiences have steered Rep. Reichert into his role as a champion for biomedical research. As he sees it, a strong, sustained commitment to biomedical research is fundamental to improving treatments for the diseases that have affected him through the experiences of his family

and friends. He said, "There are so many stories that I could share, personal stories that I could share, that inspired me to really focus on pushing NIH funding in this job."

But for Rep. Reichert, being a biomedical research champion isn't just about words – it's about actions. For example, he has strongly encouraged the National Cancer Institute, part of the National Institutes of Health, to focus on cancers that have lower success rates in finding cures, such as pancreatic cancer.

"The goal is not just to reduce the risk of death with some cancers," he explained. "The goal is to eliminate cancer. We can do that with the science and the research and development that goes on and on and on until we find cures for these diseases."

With researchers working all across the country and making significant strides toward discovering cures, survival rates for many diseases have increased dramatically. For example, the five-year relative survival rate for all cancers discovered between 1999-2005 is 68 percent, up from 50 percent in 1975-1977.¹² However, Rep. Reichert believes that continued investment in research is needed.

"I think the frustrating part is that we can make some progress, but there are still people out there suffering from these diseases. We haven't found the cures yet, and I really believe we're right on the verge of finding a cure for cancer. And you can see over the years how much progress we've made. But we need to make more progress."

"The goal is not just to reduce the risk of death with some cancers. The goal is to eliminate cancer."

Aside from the health and well-being that stem from medical research, Rep. Reichert also sees economic benefits to investing in research, including reductions in medical costs, a more productive workforce and financially stable families.

As he said, when you discover better treatments for disease, "Medical care cost is reduced. And then, of course, it gives people this hope and the opportunity to enter back into the work force and become productive members of society."

He also highlighted the "tremendous amount of stress that is placed upon the families that have to be home caregivers. Or even more stress if they have to move into a facility where the family decides 'I can't take care of my loved any longer at home.'" He detailed scenarios where a sick patient has to keep his or her job just to help pay medical bills, or a family member has to take on extra work just to help pay for medical treatment of a loved one.



Rep. Reichert and his godson, Kyle (age 14).

These are all-too-familiar experiences across the country. With the average total annual cost of care-giving reaching between \$5,331 and \$12,348, it's clear that families and patients nationwide are under financial and emotional stress to pay for treatments.

In fact, a study published last summer in the American Journal of Medicine showed that in 2007, medical bills were the cause of nearly two-thirds of all bankruptcies for people, most of whom had health insurance.

The solution – from Rep. Reichert's perspective – is to invest in our nation's research institutions to find better, more affordable treatments for patients. Without adequate funds for continued research, Rep. Reichert fears that he may hear more stories of suffering from his constituents and loved ones – and fewer success stories like that of his godson, Kyle.

He said, "It's about life and death for people. And we need to be committed to saving lives. And the government has a role to play in providing funds for research and development of these diseases.

"There are so many benefits that you can't shut the door on. It has to be done. Must be done."

"It's about life and death for people. And we need to be committed to saving lives. And the government has a role to play in providing funds for research and development of these diseases."

Representative Lucille Roybal-Allard



“I think that whenever we lose the talents and abilities of any young person, it isn’t just that person who loses, it’s also our society as a whole.”

The courage of Cynthia and Mikayla in the face of their ongoing struggles with chronic diseases was an inspiration for Rep. Roybal-Allard to become a champion for increased biomedical research funding. According to the Congresswoman, the pain and suffering these girls and their families face is just one of the reasons she fights for them. She also believes that we as a nation pay a price, not just in medical costs, but in having these vibrant young girls sidelined with illnesses.

Members of Congress often interact with their constituents but rarely do these meetings lead to lifelong inspiration. For Representative Lucille Roybal-Allard, however, two young girls from her home district in California have had a profound impact on her life.

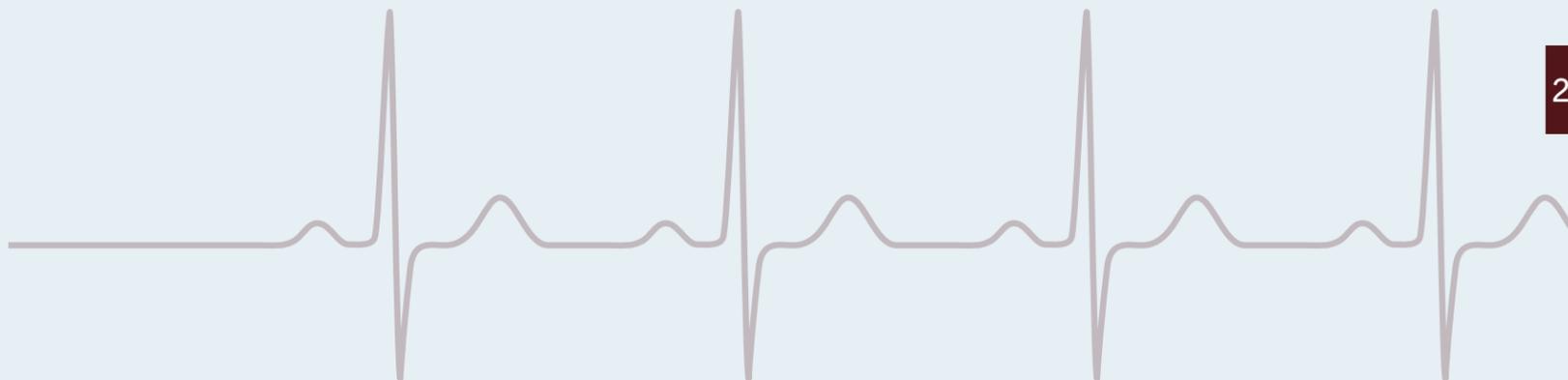
Cynthia (age 15) has scleroderma, a chronic connective tissue disease that causes skin to harden and become extremely sensitive to heat and cold. Cynthia must often wear gloves because her hands intensely react when they are cold. Congresswoman Roybal-Allard first met Cynthia when she came to Washington to testify before the Labor HHS Education Appropriations Committee about the need for scleroderma research in the spring of 2008.

For Mikayla (age 12), juvenile rheumatoid arthritis (JRA) is only one part of a very busy life. The Congresswoman became friends with Mikayla when she came to lobby for arthritis research several years ago, and last year invited the young advocate to testify before the LHHS Appropriations Subcommittee. This past summer the medication Mikayla had been prescribed failed and she was bedridden for several months, highlighting the need for additional research and improved treatments for JRA patients.

“I think that whenever we lose the talents and abilities of any young person, it isn’t just that person who loses, it’s also our society as a whole,” Rep. Roybal-Allard said. For this reason, Rep. Roybal-Allard has been a long-time champion for the National Children’s Study, a multi-year and multi-site research study that will look at the effects of environmental, cultural, family and genetic influences on the health and development of more than 100,000 children across the United States, following them from before birth until age 21.

“We don’t have the answer as to why some diseases impact a particular ethnic population versus another,” says Rep. Roybal-Allard, pointing to issues the National Children’s Study is working to uncover. “And we need to find those answers, not only to prevent human suffering but also to improve the health and prosperity of all our minority communities.” According to Rep. Roybal-Allard, the National Children’s Study is one more way that the NIH is determining the national agenda for medical research.

It’s for these reasons and more that Rep. Roybal-Allard supports increased funding for NIH. The Congresswoman strongly believes that the NIH plays a critical role in



“I just don’t understand, quite frankly, how anyone can say that we shouldn’t be investing in research and finding the answers to these terrible diseases.”

developing life saving diagnostic tests, treatments and medications to fight the diseases that threaten the health of our nation. But she also sees NIH as key in developing the critical next generation of research scientists. She continued, “Unless we invest in research, our brightest young minds will choose other careers or other countries in which to fulfill their science dreams. We as a country simply cannot afford to fall behind in our research capabilities and capacity.”

Another person who inspired Roybal-Allard was Randy Pausch, the Carnegie Mellon University professor diagnosed with pancreatic cancer at 47, who was told after a procedure designed to stop the spread of the cancer that he had three to six months to live. In those final months, Pausch gave a lecture entitled, “The Last Lecture: Really Achieving Your Childhood Dreams,” that went viral on YouTube and was eventually turned into a best-selling book called, “The Last Lecture.”

In March of 2008, shortly before Pausch passed away from complications of pancreatic cancer, Rep. Roybal-Allard invited him to testify before the LHHS Subcommittee about the need for increased pancreatic cancer research funding. Pausch “fought until the very end against a disease that offers little hope of survival,” said Rep. Roybal-Allard. As Rep. Roybal-Allard sees it, increased funding for biomedical research will help our country progress toward a future where patients won’t have to fight the same battles Randy Pausch, Cynthia and Mikayla and their families have.

“What investment in research means to them is that there’s hope; that there are people out there who are working every day to find a cure. And research also means that if a disease has a genetic or environmental component than there is hope that we can one day prevent that disease from cutting short the hopes and dreams of our next generation.” She continued, “This is absolutely essential to the future prosperity of our nation. I just don’t understand, quite frankly, how anyone can say that we shouldn’t be investing in research and finding the answers to these terrible diseases.”



Rep. Roybal-Allard and her constituent and friend, Mikayla (age 12).

Endnotes



¹ <http://www.nih.gov/about/NIHoverview.html>

² <http://www.nih.gov/about/NIHoverview.html>

³ http://www.lupus.org/webmodules/webarticlesnet/templates/new_learnunderstanding.aspx?articleid=2231&zoneid=523

⁴ <http://www.nih.gov/about/budget.htm>

⁵ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1636905/>

⁶ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1636905/> and <http://www.nih.gov/about/budget.htm>

⁷ <http://www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/cancer-facts-and-figures-2010>

⁸ http://www.ovarian.org/about_us.php

⁹ <http://www.nih.gov/about/organization.htm>

¹⁰ <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=190>

¹¹ <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=190>

¹² <http://www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/cancer-facts-and-figures-2010>

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About UMR



Because the scientific opportunities to improve human health have never been greater and the economic benefits of biomedical research have never been more important, leading research institutions, patient advocates, medical professional organizations and biomedical companies have united in support of robust funding for the National Institutes of Health (NIH).

The nation's investments in NIH have helped wipe out diseases that killed our grandparents and have led us to the brink of new discoveries in deadly and debilitating illnesses such as cancer, Alzheimer's, heart disease, diabetes, rare diseases and many more.

Indeed, NIH's mapping of the human genome and other advances in our understanding of the building blocks of life have ushered in an exciting new era of discovery, unique in history. Scientists now have the opportunity to beat back disease using new knowledge of biological structures and functions. They are no longer limited to describing an illness's symptoms, employing whatever tools are available, and watching to see what works. Instead, using the knowledge gained through more than 40 years of arduous study, researchers can now zero in strategically on a disease, identifying its triggers and crucial moments of development. Through recent discoveries and new technologies developed in the last decade alone, researchers more fully understand the molecular drivers of disease and how to affect them. This is a powerful moment in science, full of new hope for patients and new opportunities that scientists can pursue as fast as funding allows.

NIH is also an important economic engine. The large majority of NIH funding is awarded to more than 325,000 researchers in public and private research institutions across the U.S. In every state in the country, NIH-funded projects support new and experienced scientists, and numerous jobs in industries that provide research facilities, supplies and equipment. Moreover, NIH-funded research is the foundation of the U.S. biotech and pharmaceutical industries, and a vital tool for reducing the burden of disease and its associated health care costs.

At this critical moment in our nation's history, sustained investments in biosciences through the only federal agency specifically designed for this purpose —NIH —is more important than ever.

United for Medical Research (UMR) is dedicated to seeking the NIH funding necessary for delivering on the promise of this historic moment in biomedical science.

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