



**FY 2014 Public Witness Testimony**

Appropriations Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies  
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Chairman Kingston, Ranking Member DeLauro, and Members of the Committee,

Today I am speaking on behalf of the Lupus Research Institute, the nation's only nonprofit organization solely dedicated to novel, pioneering and high-risk research in lupus. We believe that innovative research is the key to finding safer and more effective treatments -- and eventually a cure for lupus.

Our primary request for your consideration as you prepare the Fiscal 2014 appropriations bill is to strengthen support for biomedical research at the National Institutes of Health by providing at least \$30 billion.

Mr. Chairman and Representative DeLauro, imagine a disease that is a leading cause of heart attack, stroke and kidney disease among young women. Imagine a disease that strikes the innocent, without warning and at random. It attacks the brain, heart, lungs, or blood -- virtually any organ. Imagine a disease with no known cause or cure. And finally, please imagine a disease that waited over 50 years before receiving its first new drug for treatment.

That disease is lupus! Although there are over 100 autoimmune disorders, lupus is the prototypic autoimmune disease. It is a major public health issue. I can assure you based on my 30 years of personal experience in clinical practice and research: this is a

dangerous, debilitating and heartbreaking disorder. It affects over one-and-a-half million persons in the United States. Ninety percent of patients are women, and the disease disproportionately affects African Americans, Hispanics, Asians and Native Americans. Lupus is three times more common in African Americans than in Caucasians. Lupus has no respect for age. It affects young children, adolescents and adults, but approximately 80 percent of new cases of lupus develop among young women, women in their childbearing years.

During the course of my career, approximately 100 of my lupus patients have died, and countless have had strokes or have gone on to kidney failure and required dialysis. I could fill the entire day with heartbreaking stories. Our goal is to cure this disease so there are no more stories.

The Lupus Research Institute was founded 12 years ago. Its driving mission has been to invest in pioneering, innovative research searching for the cause and cure. Our program has been highly successful. Fourteen new candidate biomarkers have been discovered, and some are already in clinical investigation. We are currently announcing the largest private sector grants ever awarded in lupus -- our Global Distinguished Innovator Awards program focused on the basic cause of the disease. The LRI's investment has provided academic-based investigators with the ability to initiate studies, make breakthroughs and become successful in obtaining highly competitive NIH funding to continue their research. Our hard earned private funding is leveraged at a very high rate with our investigators going on to receive subsequent NIH funding.

However, we and similar private research organizations all depend on a strong and vibrant biomedical research enterprise fueled and led by the NIH. We could never be successful without it.

Clearly, tomorrow's advances in lupus and other autoimmune diseases depend on today's investments in NIH research. Sustained, dependable, long-term growth in NIH-funded medical research brings the promise of new knowledge and technologies in pursuit of cures for patients. The fiscal climate of the past few years has threatened the stability of the biomedical research enterprise.

The first phase of sequestration now underway will cap three years of flat funding for the National Institutes of Health. As \$1.6 billion in cuts are applied over the next seven months, vital research will be delayed, halted or even abandoned. The effects on private sector researchers and institutions across the country will be devastating. Over the past 10 years, the NIH budget has effectively fallen by nearly 20 percent after inflation.

Stagnant investment will have a huge damaging and long-lasting effect on our already dwindling pipeline of young investigators. An austere research spending program will no doubt jeopardize the position of the United States as a global leader in biomedical research and development. But, the ultimate fallout is the negative impact on the nation's health.

A wide range of Institutes at the NIH support investigation into lupus. I can assure you that lupus patients rely on all types of biomedical research supported by the NIH, including basic and genomic research, translational studies and clinical trials. These activities will help lead to new treatment options and a better understanding of the mechanisms of this devastating chronic disease.

Because of research in the public and private sector, two years ago, the lupus community finally witnessed its first new drug ever approved for lupus by the FDA in more than 50 years. But that is not enough. A desperate need for safer and more effective treatment options exists.

Today, most current treatments for lupus are toxic with devastating and debilitating effects on the body. Drugs are prescribed “off label” in an attempt to control the ravages of the disease. But in attempting to control the disease, patients might also sustain bodily injury from these same treatments. For example, twenty-year-old women may need to have joint replacements because of damage caused by steroids prescribed to counter lupus symptoms. Physicians need a better arsenal of treatments.

Mr. Chairman and Representative DeLauro, racial disparities also play a key role in lupus. New initiatives are desperately needed to eliminate numerous barriers to early medical diagnosis of lupus.

In a special report to your Appropriations Committee in January 2010, the Department of Health and Human Services highlighted the effect of disparities on lupus patients. The report stated: “Many still die prematurely from lupus because of complications of the disease, late diagnosis, and co-occurring chronic conditions such as arteriosclerosis, hypertension, and diabetes.”

The report reinforces the need for efforts to ameliorate disparities, stating: “Until researchers discover a cure or new ways of identifying at risk individuals as well as diagnosing and treating lupus, educating health care professionals about the importance of early diagnosis and teaching patients how to manage and cope with lupus provide the best opportunity for improving quality of life for patients and for controlling morbidity and mortality.”

Many lupus patients often visit multiple doctors and go years before receiving a correct diagnosis. As a result, patients at the time of diagnosis can be in very acute stages of the disease. Through enhanced research efforts, we can develop new methodologies, and we must strive to permanently improve diagnosis and treatment and reduce health disparities among those suffering with lupus.

NIH research has an impressive track record of producing just such tangible improvements in the diagnosis, treatment and prevention of disease. The success of the Human Genome Project and other subsequent projects are providing a powerful foundation for a new level of understanding in human biology. A new window is opening into causes of disease, and it is now a time of great scientific discovery. Tapping into

that potential and pursuing new initiatives to bring research from “bench to bedside” can only be continued with sustained investments.

The \$30 billion level we seek in Fiscal 2014 represents a modest 2.7 percent increase and would allow the NIH to continue to innovate in areas of exceptional promise for patients. We respectfully request that you provide at least that amount in an effort to reduce the burden of disease and save lives.

We support efforts to permanently replace the need for sequestration. We respectfully urge Congress and the Administration to work together on a solution that addresses the nation’s fiscal needs while preserving the national investment in biomedical research and the health of the American people.

Mr. Chairman, Ranking Member DeLauro and Committee Members, as you develop the Fiscal 2014 appropriations bill, the Lupus Research Institute -- on behalf of patients, scientists and lupus healthcare providers -- urges your Committee to support this critically important national research agency.

I thank you and the other Committee Members for this important opportunity to appear before you today.