

NIH OFFICE OF AUTOIMMUNE
DISEASES ACT OF 1998

HON. HENRY A. WAXMAN

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Tuesday, October 20, 1998

Mr. WAXMAN. Mr. Speaker, I am pleased to introduce the NIH Office of Autoimmune Diseases Act of 1998. This bill is intended to promote discussion of how we can enhance the Federal government's response to the severe impact of autoimmune diseases and disorders on our country. Most importantly, it is intended to highlight the urgency of treating autoimmune diseases as a priority women's health issue.

Today, there are at least eighty recognized autoimmune diseases, ranging from multiple sclerosis, rheumatoid arthritis and lupus to juvenile-onset diabetes, scleroderma, Graves's disease and thyroiditis. All of these diseases and disorders are characterized by autoimmunity, the terrible case of the body's immune system rebelling against itself. Frequently inherited, these diseases and disorders lead to death or severe disability, cause a painful loss in patients' quality of life, and inflict a tremendous toll on their families and communities. Collectively, autoimmune diseases cause untold mortality and morbidity in this country, as well as billions in health care expenditures and lost productivity every year.

Yet last December, Acting Deputy Assistant Secretary for Women's Health Susan Wood observed that, "Despite their devastating human and economic toll, autoimmune diseases are among the least investigated, most difficult to diagnose, and physically and emotionally painful diseases that face Americans today."

This is a terrible and unnecessary situation. Even worse is that the disproportionate impact of these diseases on women is even less well recognized. Few people in our country know that seventy-five percent of those afflicted with an autoimmune disease are women. I doubt many of my colleagues are aware that multiple sclerosis is twice as common in women compared to men.

These statistics do not adequately reflect how important autoimmune diseases are to women. The best available research suggests that autoimmunity may be the cause of 50 to 60 percent of unexplained cases of infertility and is also a major cause of miscarriages. But these numbers only hint at the pain and doubt experienced by women and their families as a result of autoimmune diseases.

The suffering of patients from the clinical manifestations of these diseases and disorders can be exacerbated by a lack of information and understanding. A recent study by the American Autoimmune Related Diseases Association found that two-thirds of all women suffering from autoimmune diseases has been labeled "chronic complainers" before being correctly diagnosed. No woman should have to experience such insensitivity and lack of awareness when seeking care for serious diseases.

The Federal government is pursuing an agenda of research and education on autoimmune diseases. For several years, the National Institutes of Health (NIH) has supported a multi-institute research program on the

mechanisms of immunotherapy for autoimmune disease. There is an NIH research program for autoimmunity centers of excellence. And last September, several NIH institutes and the Office of Women's Health Research initiated a research program focusing on genetic susceptibility to autoimmune diseases.

But it is clear that more can be done. The NIH recently established an autoimmune diseases coordinating committee, to help facilitate the innovative research being conducted on autoimmune diseases. My colleague, Congresswoman MORELLA, has played a leadership role in this regard. The Congress has also dramatically increased NIH funding over the past few years, with the expectation that autoimmune disease research would benefit from this trend.

This bill would take these promising developments a step farther. Progress on finding cures and treatments for autoimmune diseases would surely be expedited by a permanent office at the NIH dedicated to developing a consensus research agenda, as well as promoting cooperation and coordination of ongoing research. Such an office could serve as an advisor to the Director of NIH and the Secretary of Health and Human Services, and act as a high-level liaison to the many important autoimmune disease patient groups, such as the National Multiple Sclerosis Society, American Autoimmune Related Diseases Association, the Arthritis Foundation, Juvenile Diabetes Foundation and the National Organizations for Rare Disorders.

I am introducing this legislation with the intention of fostering discussion. I look forward to working with the NIH, the Administration and patient groups on it. Upon its introduction in the next Congress, I urge my colleagues to support it as a step forward in the search for cures for autoimmune diseases.

RHODE ISLANDERS HELPING THE
DOMINICAN REPUBLIC

HON. ROBERT A. WEYGAND

OF RHODE ISLAND

IN THE HOUSE OF REPRESENTATIVES

Tuesday, October 20, 1998

Mr. WEYGAND. Mr. Speaker, I rise today to thank the many people and organizations throughout the great state of Rhode Island who united to collect much needed supplies for the humanitarian relief efforts for the victims of Hurricane Georges in the Dominican Republic. As you know, during the week of September 15, 1998, Hurricane Georges tore through the Caribbean.

From a root of tragedy has grown a stem of unity, especially among the Hispanic community. The relief supplies collected in Rhode Island by local Hispanic churches and other relief groups will go directly to the Dominican Republic—one of the islands hardest hit by Hurricane Georges. The residents of this island have suffered tremendous losses in both possessions and lives. The generosity of Rhode Islanders will help get these residents back on their feet to begin rebuilding their lives.

As the donated supplies grew in size, I was pleased to work closely with the Providence and Worcester Railroad and Sammy Sosa and the Sammy Sosa Foundation to secure trans-

portation for these much needed supplies. Both the P&W Railroad and the Sammy Sosa Foundation agreed to cover the associated costs of transporting the goods to the Dominican Republic. P&W donated the cost of the rail transportation between Rhode Island and Miami. In Miami, the Sammy Sosa Foundation will transfer the goods to a cargo ship headed to the Dominican Republic. The Sammy Sosa Foundation and the Providence and Worcester Railroad have made it possible for the residents of the Dominican Republic to receive canned food, bottled water, blankets, batteries, clothing, powdered milk, medical supplies, and other goods.

This past Sunday, a sunny, beautiful New England fall day, these groups and their volunteers joined together once again at the Pine Street Railyard in Pawtucket, Rhode Island. Everyone gathered to load the supplies that had been collected since the Hurricane first struck the island onto the huge P&W boxcar. Forming a human chain, the volunteers unloaded cars, trucks, vans, and pickups onto the car. With the help of all assembled, the long line of cars were soon emptied and the boxcar was loaded to the brim. The energy and enthusiasm of the crowd of workers was truly amazing, Mr. Speaker. I was most moved, however, to see Rhode Islanders from different walks of life—people who might not otherwise spend the day together—joining together to help those who can not help themselves.

The following organizations collected goods, donations and delivered the supplies to the departure sight in Pawtucket: WPMZ Poder 1110; Gtech Corporation; Quisqueya in Action; Rhode Island Committee for Puerto Rican Statehood; Hurricane George Relief Fund; Centro Las America, Worcester, Massachusetts; Teamsters Local 251, Providence; Teamsters Local 170, Worcester.

While many organizations offered their services, it was individuals who collected and boxed the relief supplies and then loaded them into the boxcar. While hundreds were involved at some point, a select few deserve special recognition for their efforts. I am sure I can speak for the residents of the Dominican Republic in thanking the following for their tireless efforts.

Senator Jack Reed, Jennie Rosario and Jose Mendez with the Rhode Island Committee for Puerto Rican Statehood, and Tony Mendez with WPMZ Poder 1110.

From the Providence and Worcester Railroad: Mrs. Heidi Eddins; Katherine Eddins; Scott Eddins; Brett Eddins; Mr. Norbert Cabral, Sr.; Mr. Paul Arrighi; Mr. John Corrigan; Mr. Jerald DeMello; Mrs. Diane DeMello; Mr. Robert Kraemer; Mrs. Patricia Kraemer; Mr. Larry Berg.

In addition, Mr. Art Sandoval from the Sammy Sosa Foundation deserves a great deal of thanks.

And last, but certainly not least, Mr. Sammy Sosa. When we mention the name Sammy Sosa we immediately think of the Chicago Cubs player who hit a record breaking sixty-six (66) homeruns. Sammy Sosa and his foundation have hit yet another home run, possibly the most memorable one of all, especially in the eyes of the Hispanic community in Rhode Island.