

RECOGNITION OF NATIONAL PRIMARY IMMUNE DEFICIENCY DISEASES AWARENESS WEEK

HON. JIM McCRERY

OF LOUISIANA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 21, 2004

Mr. McCRERY. Mr. Speaker, I rise today to ask my colleagues to join me in recognizing the week of April 19th as National Primary Immune Deficiency Diseases Awareness Week. Primary immune deficiency diseases are genetic disorders in which part of the body's immune system is missing or does not function properly. The World Health Organization recognizes more than 150 primary immune diseases which affect as many as 50,000 people in the United States. Fortunately, 70 percent of P.I.D.D. patients are able to maintain their health through regular infusions of a plasma product known as intravenous immunoglobulin. IVIG helps bolster the immune system and provides critical protection against infection and disease.

I am familiar with primary immune deficiencies because one of my good friends and constituents, Gail Nelson, is a P.I.D.D. patient. Gail and her husband Syd Nelson are tireless advocates for the primary immune deficiency community as volunteers for the Immune Deficiency Foundation. IDF is the nation's leading organization dedicated to improving the quality of life for P.I.D.D. patients.

Several years ago, the Nelsons educated me about the IVIG treatments that Gail and other P.I.D.D. patients receive on a monthly basis. Thanks to Gail and Syd's advocacy, I learned that the optimal setting for many P.I.D.D. patients to receive their IVIG infusions is in the home. Not only is home infusion more convenient for patients, it eliminates the potential for individuals to be exposed to infectious agents in a doctor's office or hospital outpatient setting. Despite the clear benefits of home infusion, I was disappointed to learn that Medicare would only pay for the administration of IVIG in an outpatient setting or a doctor's office.

As Congress undertook its landmark effort last year to modernize the Medicare program, I was pleased to work with my colleagues on the Ways and Means Committee to include a provision in the legislation to extend coverage for the home infusion of IVIG. This important provision provides coverage for home infusions if the Medicare beneficiary is (1) a diagnosed primary immune deficiency patient, and (2) has received clearance from his/her physician to receive treatment in the home. This important provision makes a new treatment option available for Medicare patients that has been the standard of care for many P.I.D.D. patients on private insurance.

Mr. Speaker, despite the important progress we have made in treating primary immune deficiencies, the average length of time between the onset of symptoms and a definitive diagnosis of P.I.D.D. is 9.2 years. In the interim, those afflicted may suffer repeated and serious infections and possibly irreversible damage to internal organs. That is why it is critical that we raise awareness about these illnesses within the general public and the health care community.

Mr. Speaker, I commend the Immune Deficiency Foundation for its leadership on behalf

of the P.I.D.D. community, and I am proud to join them in recognizing the week of April 19 as National Primary Immune Deficiency Diseases Awareness Week. I encourage my colleagues to work with us to help improve the quality of life for P.I.D.D. patients and their families.

NATIONAL MINORITY CANCER AWARENESS WEEK

HON. ELLEN O. TAUSCHER

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 21, 2004

Mrs. TAUSCHER. Mr. Speaker, I rise today to speak in support of National Minority Cancer Awareness Week.

This year marks the 18th annual National Minority Cancer Awareness Week, a national awareness campaign which focuses on the disproportionate cancer burden experienced by racial and ethnic minorities and other medically underserved communities.

Despite all the progress that has been made in the battle against cancer, there is still much work to be done to eradicate this horrible disease.

In California alone, 125,000 new cancer cases will be diagnosed this year; 52,200 people will die from cancer. Out of every 100,000 people living in California, 186 will eventually die of cancer.

Mr. Speaker, we all know that a disproportionate burden of cancer continues to fall on a number of populations. African Americans have the highest death rates for all cancers and cancer is the leading cause of death for Asian American women.

According to the Centers for Disease Control, the average annual death rate per 100,000 people for all types of cancers was 257 for African Americans, 199 for whites, 138 for Hispanic-Americans, 138 for American Indians, and 125 for Asian/Pacific Islanders.

For every 100,000 people living in California, 65 African Americans in that group will die each year from lung cancer, 17 Hispanic women will die from breast cancer and 13 Asian Americans will die from prostate cancer.

Inadequate access to preventive services and early detection means that diseases like cancer are more often diagnosed at later stages when the severity is likely to be greater and options for treatment are decreased.

The future health of America as a whole will be influenced substantially by our success in improving the health of minority and other medically underserved populations.

I rise today to commend those working in my district and state who work tirelessly on this issue in the hopes of one day beating cancer.

Mr. Speaker, I urge my colleagues in Congress to come together and find a way to fund crucial research into cures for this disease. I hope we can reduce and ultimately eliminate the disproportionate burden cancer and other diseases pose on minority and medically underserved communities in our country.

RECOGNIZING NATIONAL PRIMARY IMMUNE DEFICIENCY WEEK

HON. DAVID E. PRICE

OF NORTH CAROLINA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 21, 2004

Mr. PRICE of North Carolina. Mr. Speaker, I rise today to ask my colleagues to join me in recognizing the week of April 19th as National Primary Immune Deficiency Diseases Awareness Week. Primary immune deficiency diseases (PIDD) are genetic disorders in which part of the body's immune system is missing or does not function properly. The World Health Organization recognizes more than 150 primary immune diseases which affect as many as 50,000 people in the United States. Fortunately, 70 percent of PIDD patients are able to maintain their health through regular infusions of a plasma product known as intravenous immunoglobulin. IVIG helps bolster the immune system and provides critical protection against infection and disease.

I am familiar with primary immune deficiencies because of the work that is being done in my district by Dr. Rebecca Hatcher Buckley. Dr. Buckley is Chief of Pediatric Allergy and Immunology at Duke University Medical Center, and she is the leading expert and pioneer in the diagnosis and treatment of Severe Combined Immune Deficiency (SCID) also known as "bubble boy syndrome." Children diagnosed with SCID lack an immune system, which is essential to survival. Dr. Buckley has dedicated her life to helping to save the lives of babies born with SCID through early diagnosis and treatment.

Although newborn screening exists for SCID, states do not include the test among their required screenings. Additionally, despite the recent progress in PIDD research, the average length of time between the onset of symptoms in a patient and a definitive diagnosis of PIDD is over 9 years. In the interim, those afflicted may suffer repeated and serious infections and possibly irreversible damage to internal organs. That is why it is critical that we raise awareness about these illnesses within the general public and the health care community.

Mr. Speaker, I commend the Immune Deficiency Foundation for its leadership in this area, and I am proud to join them in recognizing the week of April 19th as National Primary Immune Deficiency Diseases Awareness Week. I encourage my colleagues to work with us to help improve the quality of life for PIDD patients and their families.

PAYING TRIBUTE TO SR. MARGARET "PEG" DOLAN, R.S.H.M. ON THE 50TH ANNIVERSARY OF HER ORDINATION IN THE RELIGIOUS SACRED HEART OF MARY

HON. MAXINE WATERS

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 21, 2004

Ms. WATERS. Mr. Speaker, I rise to recognize and pay tribute to one of my most distinguished constituents, Sr. Margaret "Peg" Dolan, R.S.H.M. I commend her to my colleagues and thank her for her service to Loyola Marymount University, to Los Angeles, and