

Wednesday, February 22, 1995

Mr. ORTIZ. Mr. Speaker, today, I am joined by a bipartisan group of Members in introducing a bill whose objective is to reduce the rate of birth defects in this country. I am particularly pleased that my colleague from Texas, Congressman HENRY BONILLA, is the lead cosponsor of this vital legislation. The legislation addresses a national health care issue that crosses all geographic areas and affects children of all races and economic classes and is imperative to the public health of all Americans.

Many people may not realize that birth defects are the leading cause of infant mortality in the United States as well as a leading cause of disability and shortened life expectancy. Currently, over 150,000 children are born with a serious birth defect every year. Nevertheless, the United States lacks a coherent, comprehensive national strategy to address the birth defects problem. As a result, there are inadequate State and local resources that work to combat the incidence of birth defects. Consequently, most Americans have insufficient knowledge about birth defects, and remain unaware of the high rate of birth defects in our country.

This legislation, in many ways, is a product of a tragedy in part of my district, Cameron County, TX. It is the result of great anguish and misery experienced by mothers, fathers, and all who sympathize with the loss of a child, or the sadness of a baby born with a deformity.

The discovery of this tragedy began to unfold in March 1991, when a nurse helped deliver two babies in a 36-hour period. Both babies had anencephaly, a lethal birth defect in which the baby either has only a partial brain or no brain at all. This pattern triggered this competent nurse to review recent hospital birth records where she found a pattern of six babies born with anencephaly in the previous month.

The Texas Department of Health and the Centers for Disease Control were notified of the extremely high rate, and a case study of the cluster was initiated. Further research by the Centers for Disease Control and the Texas Department of Health revealed even more anencephaly cases, the largest cluster of such cases ever recorded in such a short period of time in the United States.

The revelation of this cluster created an atmosphere of anxiety and fear in this close-knit community along the United States-Mexico border. Families expecting or planning to one day have a child were fearful of the possibility of anencephaly. Many have put family plans

on hold. Much has been revealed with the unfolding of this intense investigation, which has included an examination of environmental, nutritional, and genetic factors.

First, we have learned that folic acid has proven to be effective in reducing the recurrence of neural tube defects and may possibly reduce the chance of initial occurrence. In fact, in September 1992, the U.S. Public Health Service issued a recommendation on folic acid stating that all women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg of folic acid per day for the purpose of reducing the risk of having a pregnancy affected with spina bifida or other neural tube defects. The discovery that folic acid can contribute to preventing neural tube birth defects could save many babies each year from disability and death. This news is greatly welcomed.

The events in Brownsville, TX, also called attention to the fact that the prevalence of neural tube defects in Hispanic children was twice the national average. Additional studies show that the Hispanic community, on a nationwide level as well as in some Latin American countries, seems to experience higher rates of anencephaly and other neural tube defects than other ethnic groups.

In order to address the issue of birth defects, this legislation seeks to establish a national, State-based, birth defects surveillance system with regional centers of excellence to determine the unknown causes of birth defects. The bill also enables States to begin or enhance their own birth defects registries. This will ensure that basic information on birth defects can be gathered and analyzed so clusters like that in Cameron County would not have to be discovered accidentally.

The bill also establishes regional birth defects centers of excellence whose purpose is to monitor the changes in the incidence of birth defects by studying surveillance information. This will create a mechanism so that we can act quickly when a cluster is identified, thereby alerting and directing all pertinent Federal, State, and local agencies so that all possible causes, whether environmental, nutritional, or genetic, will be explored. These centers will develop and evaluate preventive services so that we can work to prevent birth defects, and not act in instances after the fact.

The bill also establishes a clearinghouse at the Centers for Disease Control so that information is centralized. We must have the capability of collection, storage, and interpretation of data generated from State birth defects surveillance programs and regional birth defects centers, as well as the ability to disseminate that information in a timely and useful manner.

The Centers for Disease Control is the Federal agency charged with protecting the public

ease Control was obviously the best choice as the lead agency to coordinate the Federal, State, and local efforts for this national birth defects program.

In these times of budgetary constraints, many may have concerns about the cost of this bill. A close examination, however, will show that this bill will actually serve to reduce expenditures. It will help save money by reducing the incidence of birth defects, which cost the States and the Federal Government millions of dollars each year in treatment, special education, insurance, and loss of income.

This legislation has already gained bipartisan support, and I am thankful that it has the blessing of so many distinguished Members, particularly Congressman HENRY BONILLA. Additionally, I would like to thank Senator BOND for his lead on this legislation in the Senate. I would also like to thank the March of Dimes for their invaluable contributions and dedication to working toward the prevention of birth defects. The March of Dimes' commitment toward enacting the Birth Defects Prevention Act of 1995 only strengthens this legislation. Other major health organizations have also endorsed this legislation, and I am pleased to submit a list for the record.

The concept of this bill may have derived from a crisis in Brownsville, TX, however, its provisions are important to the Nation as a whole. Birth defects are not simply a regional problem, they are a health issue that should be addressed seriously by all Americans. The Birth Defects Prevention Act of 1995 will serve as an investment in the health of all people of the United States.

Mr. Speaker, I urge my colleagues to support the bipartisan Birth Defects Prevention Act of 1995 by cosponsoring this legislation.

#### NATIONAL ORGANIZATIONS ENDORSING THE BIRTH DEFECTS PREVENTION ACT OF 1995

American Academy of Pediatrics, American Association of Mental Retardation, American Association of University Affiliated Programs, American College of Medical Genetics, and American Counseling Association.

American Mental Health Counselors Association, American Occupational Therapy Association, American Public Health Association, American Speech-Language-Hearing Association, and The Arc.

Epilepsy Foundation of America, Learning Disabilities Association of America, March of Dimes Birth Defects Foundation, National Association of Children's Hospitals and Related Institutions, and National Center for Learning Disabilities.

National Easter Seal Society, National Society of Genetics Counselors, Society of Craniofacial Genetics, Spina Bifida Association of America, and Teratology Society.

February 17, 1995.

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