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(Original Signature of Member)

119TH CONGRESS
2D SESSION

H. RES. ______

Designating November 7 of each year as ''Shwachman Diamond Syndrome Awareness Day''.

IN THE HOUSE OF REPRESENTATIVES

Mr. KEAN submitted the following resolution; which was referred to the Committee on ________________________________

RESOLUTION

Designating November 7 of each year as ''Shwachman Diamond Syndrome Awareness Day''.

Whereas, Shwachman-Diamond syndrome (SDS) is a rare genetic disorder that primarily affects a diagnosed individual's bone marrow, pancreas, and skeleton; and

Whereas, SDS is inherited in an autosomal recessive manner, meaning a person must inherit two faulty copies of the gene, one from each parent, for the disorder to develop; and

Whereas, typically, the parents of the affected individual do not show signs and symptoms of SDS; and

Whereas, An estimated 2000 Americans are living with SDS; and

Whereas, This rare condition occurs in approximately 1 in 80,000 newborns; and

Whereas, Infants with SDS are born with the condition and develop symptoms usually by 4 to 6 months of age; and

Whereas, Individuals diagnosed with SDS often develop liver dysfunction, dental problems, developmental delays, and delayed puberty; and

Whereas, One of the main characteristics of SDS is bone marrow dysfunction; and

Whereas, Bone marrow dysfunction leads to the production of too few white blood cells, which are essential for fighting infections, making individuals more prone to frequent or severe illnesses; and

Whereas, In addition to having too few white blood cells, individuals with SDS may also have low levels of red blood cells, which increases their risk of developing blood disorders such as acute myeloid leukemia; and

Whereas, Another hallmark of SDS is pancreatic insufficiency, in which the pancreas does not produce enough digestive enzymes. This often causes problems absorbing fats and nutrients, leading to chronic diarrhea, poor weight gain, and failure to thrive, especially during infancy and early childhood; and

Whereas, Skeletal abnormalities affecting the growth plates of bones are also common in individuals diagnosed with SDS, often leading to short stature and orthopedic problems with their hips and knees; and

Whereas, With modern treatment options and ongoing management, most children diagnosed with SDS lead normal lives, although continued medications and regular monitoring are usually required; and

Whereas, Because the signs and symptoms of SDS are variable and can be mild in some affected individuals, the condition is underdiagnosed; and

Whereas, Diagnosis is based on a combination of clinical symptoms, blood tests, stool tests for digestive enzyme levels, and confirmation through genetic testing; and

Whereas, Treatment typically involves managing symptoms, such as using pancreatic enzyme replacement therapy, nutritional support, and medications that stimulate white blood cell production; and

Whereas, There is no cure for SDS. Current treatment options only lessen symptoms and treat complications; and

Whereas, SDS reduces life expectancy by more than 30 years and many patients die as infants, kids, or teens due to SDS-related complications; and

Whereas, Regular monitoring is essential to identify any progression to more serious bone marrow conditions; and

Whereas, While there is no cure for SDS, early diagnosis and multidisciplinary care can significantly improve the quality of life for diagnosed individuals; and

Whereas, As a result of its rare nature, SDS is not widely known. This has led to limited research and understanding of the disease; and

Whereas, It is appropriate to improve public awareness and understanding of this rare genetic condition, encourage support for those individuals who have been afflicted by

SDS, and promote more initiatives at the national, state, and local levels to enhance research into treating this disease; now, therefore,

Resolved, That by the House of Representatives—

(1) November 7 of each year shall be designated as ‘‘Shwachman Diamond Syndrome Awareness Day’’ to increase awareness of this heritable rare genetic disorder and its impact on the residents of this Nation, and to promote further research into effective treatments for this disease.

(2) The President is respectively requested to annually issue a proclamation recognizing November 7 of each year as ‘‘Shwachman Diamond Syndrome Awareness Day’’, and call upon public officials and the citizens of the United States to observe the day with appropriate activities and programs.

(3) This act shall take effect immediately.