

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

ASSEMBLY JOINT RESOLUTION No. 119

STATE OF NEW JERSEY

DATED: JUNE 11, 2026

The Senate Health, Human Services and Senior Citizens Committee reports favorably Assembly Joint Resolution No. 119.

This resolution designates November 7 of each year as “Shwachman Diamond Syndrome Awareness Day.”

Shwachman-Diamond syndrome (SDS) is a genetic disorder that primarily affects a diagnosed individual’s bone marrow, pancreas, and skeleton. 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. This rare condition occurs in approximately 1 in 80,000 newborns. Infants with SDS are born with the condition and develop symptoms usually by 4 to 6 months of age. With modern treatment options and ongoing management, most children with SDS lead normal lives, although continued medications and regular monitoring through hospital visits are usually required.

One of the main characteristics of SDS is bone marrow dysfunction. 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. In addition to producing too few white blood cells, some people diagnosed with SDS may have low levels of red blood cells and are at increased risk for developing blood disorders such as acute myeloid leukemia. Another hallmark of SDS is pancreatic insufficiency, where the pancreas fails to produce enough digestive enzymes. This leads to problems with absorbing fats and nutrients, resulting in chronic diarrhea, poor weight gain, and failure to thrive, especially in infancy and early childhood. Skeletal abnormalities affecting the growth plates of bones are also common in individuals with SDS, often leading to short stature and orthopedic problems with their hips and knees.

An estimated 2,000 Americans are living with SDS. Because the signs and symptoms of SDS are variable and can be mild in some affected individuals, the condition is underdiagnosed. Treatment typically involves managing symptoms, such as using pancreatic enzyme replacement therapy, nutritional support, and medications that stimulate white blood cell production. There is no cure for SDS. Current treatment options only lessen symptoms or treat

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

Recognizing November 7 of each year as “Shwachman Diamond Syndrome Awareness Day” in New Jersey will help increase awareness of this heritable rare genetic disorder and its impact on the residents of this State, as well as promote continued research into finding a treatment for this condition.