You Can Help

Shwachman-Diamond Syndrome Foundation (SDSF) is a 501c3 non-profit organization. Our federal ID # is 43-1709945. Over 95% of all donations go directly to research and family support.

We rely on caring individuals, like you, to continue our work. We want a future for SDS patients in which we can eliminate the primary cause of death, and improve the quality of their lives. To do this we must FUND RESEARCH.

Please consider making a financial gift to SDSF. You may donate online at:

www.shwachman-diamond.org

or by mail at:

Shwachman-Diamond Syndrome Foundation P.O. Box 6723 Florence, KY 41022

BE A SUPER SUPPORTER!

Monthly donations are greatly appreciated.



Please Contact Us for More Information

We are here to answer your questions, help you set up a fundraiser, and recommend physicians who are experts in treating SDS.

Please contact us if you would like additional written materials about SDS.

Web: www.shwachman-diamond.org
Email: info@shwachman-diamond.org
Phone: 1-888-825-SDSF (7373)



Support...Research...Cure





treatments

Our Mission

Since 1994, we have provided education, answers, support, and hope to SDS patients and their families. We advocate for and fund research to improve treatment and, hopefully, find a cure.

Our website, Facebook page, and newsletter provide education and support.

We sponsor a week-long family conference where patients and their families can meet face-to-face and hear the newest information from SDS medical experts.

We attend medical conferences to provide information and raise awareness about this rare disease.





What Is SDS?

Shwachman-Diamond Syndrome (SDS) is a rare, genetic, bone marrow failure syndrome that occurs in about 1 in 77,000 live births.

SDS affects many body systems including bone marrow, blood, pancreas, skeletal system, teeth, immune system, and the brain. SDS is associated with an increased risk of leukemia, myelodysplastic syndrome, and aplastic anemia.

Early signs of SDS often appear in infancy and include failure to thrive, severe or frequent infections and low blood counts.

Early diagnosis is helpful for improving quality of life and the prevention of serious complications.

About 90% of SDS patients are diagnosed through mutations on the SBDS or the EFL1 gene. The remaining 10% of SDS patients are diagnosed based on clinical symptoms.

Since SDS was first described in 1964, treatment options and prognosis have improved dramatically. There is currently no cure for SDS.

WE WILL NOT STOP UNTIL A CURE IS FOUND!

www.shwachman-diamond.org

Better treatment and a cure

The advancement of scientific knowledge and research is imperative to finding a cure for SDS. SDSF funds **research grants** in all areas affected by SDS.

We sponsor and support the SDS **International Scientific Congress** which brings together experts, researchers, and clinicians from all over the world to share their latest findings.

We support the **SDS Registry**. The SDS Registry collects and studies clinical information and samples from patients and their families to facilitate high-impact research collaborations.

