

WHY CARE ABOUT RARE?

Shwachman-Diamond Syndrome

Shwachman-Diamond syndrome (SDS) is an inherited rare disease that impacts the whole body. SDS patients often are unable to digest food, suffer poor growth, and are prone to life-threatening infections, leukemia, and other blood disorders. Many SDS patients die of complications of SDS before they reach adulthood.

RARE DISEASE FACTS

Rare diseases are not rare and can strike any family any time. There are approximately 7,000 rare diseases that together affect 30 million Americans and 40% of families.

Signs of a rare disease may appear before or at birth, in early childhood, or later. Many are fatal.

Most rare diseases are genetic; over 90% of rare diseases have no treatment, let alone a cure.

SDS FACTS

An estimated 2000 Americans are living with SDS; 1 in 75,000 births. Most doctors have never seen it and diagnosis can be challenging.

SDS reduces life expectancy by more than 30 years and many patients die as infants, kids, or teens.

There is no cure for SDS. Current treatment options can only lessen symptoms or treat complications.

HOW CAN YOU HELP?

DONATE



Donate to the Shwachman-Diamond Syndrome Foundation. Your donation helps fund research for a cure and support families with SDS patients.



Raise awareness and learn more about SDS at www.shwachman-diamond.org. Awareness helps patients get diagnosed and access better treatments and support sooner.



Join the Be The Match Registry*: become a potential blood stem cell donor. 1 in 3 SDS patients will need a bone marrow transplant in their lifetime. *join.bethematch.org/SDSF



Contact your Congress** member and urge them to fund rare disease research! Rare diseases affects nearly every other American family. We need our government to tackle this problem.

**<https://rarediseases.org/advocate/policy-priorities/contact-representatives>



WHY DO ZEBRAS REPRESENT RARE DISEASE?

Doctors are taught, "When you hear hoofbeats, think of horses, not zebras." But actually, sometimes it is a zebra--i.e., a rare disease.

