

Shwachman-Diamond Syndrome (SDS)

SPOTLIGHT

Flyer Series

ICD-10 CODE D61.02

"ICD" is short for the "International Statistical Classification of Diseases and Related Health Problems." Globally, it's the go-to classification system in healthcare, used by government bodies and researchers for monitoring and reporting various health issues, from diseases to injuries. Overseen by the World Health Organization (WHO), the ICD system has a history that stretches back to 1893, having evolved through 11 major updates since then. While the US and another 150 countries utilize ICD-10, the WHO has released the next revision, ICD-11, in 2022. However, each country transitions to new ICD editions at its own pace, sometimes taking years for full integration. We anticipate that the US will stay on ICD-10 for many more years to come.

Up until 2023, SDS did not have its own code anywhere in the world. But through the efforts of the SDS Alliance and its partners, a new code was established for SDS in the US.

ICD-10 code D61.02 for Shwachman-Diamond Syndrome takes effect on October 1st, 2023.

Why did SDS get ICD-10 code D61.02 assigned?

CHAPTER	CATEGORY	SUBCATEGORY
DISEASES OF THE BLOOD AND BLOOD-FORMING ORGANS AND CERTAIN DISORDERS INVOLVING THE IMMUNE MECHANISM (D50-D89)	APLASTIC AND OTHER ANEMIAS AND OTHER BONE MARROW FAILURE SYNDROMES (D60-D64)	D61 OTHER APLASTIC ANEMIAS AND OTHER BONE MARROW FAILURE SYNDROMES D61.0 CONSTITUTIONAL APLASTIC ANEMIA

The diagram shows the ICD-10 coding structure. It starts with Chapter D61 (Other aplastic anemias and other bone marrow failure syndromes), then Category D61.0 (Constitutional aplastic anemia), and finally Subcategory D61.02 (Shwachman-Diamond Syndrome). A blue box highlights the D61.02 code, with an arrow pointing to it from the text 'D61.02 NEW Code for SDS'.

Health Issue > **Healthcare Encounter** > **Coding in the EHR**

Inflamed mosquito bite > **ER visit: workup and treatment** > **Codes are added to the electronic health record: symptoms and treatments**
New: also root cause SDS

Whenever someone goes to the doctor with an issue, the provider's team will enter their symptoms and diagnoses into the ICD coding system that precisely - or as precisely as possible - defines what is wrong. Insurance companies use these codes to help determine coverage for interventions provided. The codes also make it into large databases - but without personal patient information such as their name or contact information to protect their privacy. These large databases allow researchers to search the data to answer various health-related research questions.



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The ICD-code resource by the Everylife Foundation further explains:

“As described by the WHO, maintenance and use of this standard classification systems allows for:

- Easy storage, retrieval and analysis of health information for evidenced-based decision-making
- Sharing and comparing health information between hospitals, regions, settings and countries
- Data comparisons in the same location across different time periods.

Consider the power of understanding which types of medical specialties are diagnosing a particular rare disease or having the ability to track changes in patients' health outcomes after a new therapy is approved for their disease. A payer's medical policy decisions for a new therapy might be based on an assessment of how many individuals covered by their plans have a particular diagnostic code in their record. These are the types of queries made possible through ICD codes. They are also the types of assessments that can be distorted by imprecise or out-of-date codes.”

And that is why we need YOUR help!

To achieve the benefits described above, it is critical that doctors, other healthcare providers, and their teams use the SDS code (D61.02) every time they see an SDS patient. We have developed a tool kit (below) to help you spread the word.

- Share this flyer with all healthcare providers who may encounter SDS patients.
- Order sticky notes on our website (QR code on top) and hand them to all healthcare providers at all upcoming appointments.
- Share this information with all SDS families in the US. Social media is a great option.
- Fill out the emergency form (available on our website) and carry it with you in case of an emergency. It includes the ICD-10 code.
- Professionals: please spread the word in your networks.



www.SDSAlliance.org/icd

Print and distribute flyers to your healthcare team



Tell all your SDS friends in the US community



Order and share sticky notes and give them to your doctor at your visit



Message all your doctors and healthcare providers



Fill and carry with you emergency medical info sheet



SDS ICD-10 TOOLKIT