

SDS Registry 2025 Winter Newsletter



SDS Registry investigations have shown improvements in early transplant outcomes and provided a deeper understanding of MDS/AML risk in patients with SDS. This past December, the SDS Registry was invited to present two key research studies at the 2024 American Society of Hematology meeting in San Diego, highlighting this progress in SDS research. This important work would not have been possible without the involvement of SDS Registry participants and valuable collaborations with international partnerships.



"Outcomes of Hematopoietic Stem Cell Transplantation for High-Risk Marrow Features without Malignancy in Shwachman-Diamond Syndrome"

This study observed excellent and superior early outcomes in SDS patients transplanted for high-risk marrow features compared to patients transplanted for MDS or AML.

Updates to be presented at the 2025 SDS Congress

"Incidence of Myeloid Malignancy in Shwachman-Diamond Syndrome: An International Cohort Study"

This international collaboration created the largest cohort of SDS patients to date and identified a high lifetime risk of myeloid malignancy in the SDS population.

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