



Spring 2024

UPDATES FROM THE SDS REGISTRY



The SDS Registry team participated in the 65th American Society of Hematology (ASH) Annual Meeting and Exposition this winter. We presented research from the SDSR and established collaborations with providers from around the world.

SDSR investigator, Dr. Helen Reed, presented her work on lymphoid malignancy in Shwachman–Diamond Syndrome during the ASH Scientific Workshop on Germline Predisposition to Hematopoietic Malignancies and Bone Marrow Failure. The study from the SDSR found an increased risk of lymphoma among patients with SDS compared to the general population. The patients with SDS who had been diagnosed with lymphoma achieved remission after therapy but experienced increased toxicity with standard chemotherapy regimens. Subsequent AML was observed in one patient following treatment with lymphoma. This study expands our understanding of potential medical complications of SDS and informs treatment decisions.

SDSR Co-Director, Dr. Kas Myers, was invited to discuss the long-term outcomes and complications in inherited bone marrow failure syndromes, including Shwachman–Diamond Syndrome. Education of medical providers is an important priority of the SDSR. Advances in medical care are made possible by the medical records and samples provided by SDSR participants.



SDSR investigators together with the French Neutropenia Registry brought together a group of SDS experts from around the world to develop an international collaborative project studying leukemia risk in SDS.

