

# The SDS Registry

**SDSF would like to encourage every patient with SDS and SDS-like to register in the North American Shwachman Diamond Syndrome Registry.**

**The more data that is available to doctors and researchers, the faster they can help with diagnosis, treatments and hopefully a cure!**

## Current Registry Investigators

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## What is the North American SDS Registry (SDSR)?

Since SDS is a rare disorder, our understanding of the medical complications and best treatments for SDS are limited. For this reason, the SDSR was established to collect medical information and clinical samples on all individuals with SDS and SDS-like across the United States and Canada with the goal of improving diagnosis and treatment. The SDSR is headquartered at the Fred Hutchinson Cancer Research Center in Seattle with collaborating centers in Toronto and Cincinnati. The SDSR is a research organization dedicated to gathering and analyzing information about SDS and sharing any new knowledge with the SDS community and medical professionals. Scientific studies using collected blood and bone marrow cells will focus on elucidating the causes of SDS and its complications in order to develop better

## How can you participate in the SDSR?

Patients can enroll in the registry by contacting the Registry coordinator, Melissa Alvendia at 206-667-6965 (toll-free 1-866-792-5876).

After signed informed consent is obtained, the patient or parents (if the patient is a minor) will receive a brief questionnaire which will be updated annually. Additional information is obtained from medical records, laboratory and pathology reports. Clinical samples are obtained when blood, bone marrow or other tissues are being obtained for clinical care, so no extra procedures are involved.

## How much will this Registry cost me?

There is no charge to you for your participation in this Registry.