

SHWACHMAN-DIAMOND SYNDROME REGISTRY

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WHY IS THE SDS REGISTRY (SDSR) NEEDED?

SDS is a rare condition, so information about SDS is scarce. More information is needed to improve the diagnosis and treatment of children and adults with SDS.

The SDSR provides a way for any patient with SDS or an SDS-like condition to share their information, experiences, and samples with researchers working to find a cure for SDS.



WHAT DOES THE SDSR DO?

By studying medical records and biological samples from the same patients over time, the SDSR works to enhance SDS diagnosis, improve treatment, and advance our understanding of risk factors for severe complications.

Samples for the SDSR are collected when they are obtained for clinical care, so no extra visits or needle pokes are needed.

WILL MY IDENTITY BE SHARED?

Data and samples are de-identified for research. None of your personal information will be shared outside the study team.



WHO WILL HAVE ACCESS TO THE SDSR?



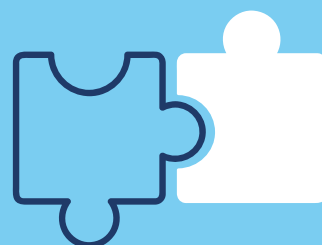
SDSR databases are password-protected behind a firewall and can only be accessed by designated members of the SDSR study team.

Only de-identified data and samples are provided to qualified investigators who will study these to improve the lives of people with SDS.

HOW WILL SHARING MY SDS EXPERIENCES AND SAMPLES HELP?

Your information and samples are critically important to advance knowledge about this rare condition with the goal of finding a cure. Here are some examples of ongoing research made possible by the data and samples collected through the SDSR:

- Understand the medical complications of SDS and their progression over time
- Develop strategies to monitor for and prevent complications such as leukemia
- Guide recommendations for medical care to improve the health of people with SDS
- Elucidate the causes of SDS
- Develop better therapies for SDS

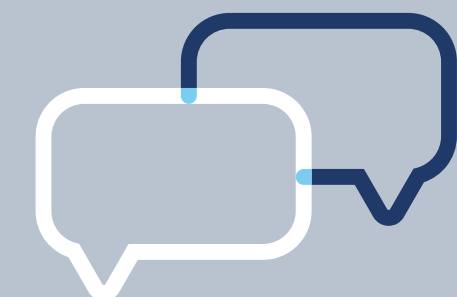


For a rare disease like SDS, every patient makes a difference.

HOW CAN I GET INVOLVED?

If you would like to partner with the SDSR in the quest for a cure to SDS, please reach out to our team at SDSRegistry-dL@childrens.harvard.edu.

If you would like to learn more about the SDSR or have any questions about SDS, you are welcome to contact the Registry team.



INTERESTED IN LEARNING MORE?

CHECK OUT OUR WEBSITE:

SDSREGISTRY.ORG

