

Virginia Statewide Sickle Cell Disease Registry

Helping improve care for individuals with sickle cell disease

About the Virginia Statewide Sickle Cell Disease Registry

The Virginia Sickle Cell Disease Registry is a secure database. It houses important information about sickle cell disease (SCD) in the Commonwealth. This information helps public health officials improve care.

- Improved diagnosis
- Improved treatment
- Improved services

In July 2024, the Virginia General Assembly passed a [law](#) that required the Virginia Department of Health to create the Registry. VDH began collecting information for the registry in 2025. (<https://bit.ly/47elBOz>)



How does the Registry help?

Increases Access to Care and Referrals. Helps improve referrals and may bring more support services to you.

Improves Diagnosis and Treatment. The Registry will help doctors and public health experts learn more about the disease. This will help improve how healthcare professionals diagnose and treat SCD.

Improves Care. The Registry will be used to identify needs of those living with SCD. Public health experts will use the information to improve services and care.

Supports Research. The Registry will allow public health researchers to better understand:

- How common SCD is in the Commonwealth
- Risk factors
- Survival rates

This information will be used to help improve quality of life for those living with SCD.

Amplifies Your Voice. The Registry will increase knowledge about your experience and your needs. Public health experts and legislators can use this to work for changes that benefit you.

Information collected is confidential.

Information reported includes your name, address, sex at birth, race, ethnicity, and gender. It also includes your type of sickle cell disease. The Registry is confidential by federal law, known as HIPAA.

If you choose not to have your data reported to the Registry you can do one of the following.

Tell your healthcare provider

Fill out the form at <https://redcap.link/scdregistry>.

Use the QR code provided here. →



Any questions ? Reach out to us at sicklecellregistry@vdh.virginia.gov

You are making a difference in the lives of people with Sickle Cell Disease.