WELCOME TO OUR

# Sickle Cell Community Hub

*we're so glad you're here!*

## THE DANIELLE DENISE SCHOLARSHIP $1000 AWARD

Danielle Denise Green was born March 31, 1975 in New York. She lived a normal, healthy and happy life in Charleston attending school and playing with friends.

She experienced one crisis and passed suddenly from sickle cell disease at the age of four on November 6, 1979.

At that time her parents didn't know they both had the sickle cell trait.

The family of Danielle Denise Green has created a scholarship in remembrance of her life.

Danielle's family wants a special recipient to claim the scholarship, someone with sickle cell disease who is doing all that they wish Danielle could have done.

The recipient of this award should be a South Carolina resident and student with sickle cell disease who has been accepted into an accredited college. The recipient should be able to demonstrate a consistent record of community service.

To apply, submit an essay about what your life has taught you, including a cover sheet with your name and contact info, your parents' names and contact info, and the name of your high school. Two letters of and documentation of your high school graduation or GED are also required.

The deadline for submission is August 31st for fall semester or December 1st for spring semester.

For more information, CONTACT Pastor Doris Haynes, Project Coordinator, faithworkshaynes@gmail.com

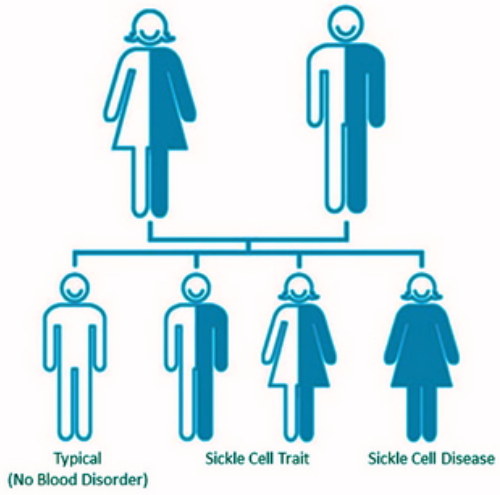
Please read submission details, along with information about the foundation, here: →

HTTPS://SITECORE.WEB.MUSC.EDU/-/SM/MEDICINE/DEPARTMENTS/PHS/F/DANIELLE-DENISE-SCHOLARSHIP.ASHX

# BE IN THE KNOW!

If both parents are SCD carriers:

- 1 in 4 chance each child they have will not inherit any SCD genes
- 1 in 2 chance each child they have will just inherit a copy of the SCD gene from 1 parent and be a carrier
- 1 in 4 chance each child they have will be born with sickle cell disease




## Get the scoop on how sickle cell disease is inherited

Genes come in pairs. You inherit 1 set from your mother and 1 set from your father. To be born with sickle cell disease, a child has to inherit a copy of the sickle cell gene from both their parents.

This happens when both parents carry the sickle cell gene, also known as having the sickle cell trait, OR when 1 parent has sickle cell disease and the other carries the trait.

Sickle cell carriers do not have sickle cell disease themselves, but there's a chance they could have a child with sickle cell disease if their partner is also a carrier of the sickle cell trait.

For More information: www.nhlbi.nih.gov/health/sickle-cell-disease.

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# SICKLE CELL DISEASE PROVIDERS AT MUSC

## Temeia D. Martin, MD

INTERNAL MEDICINE. PSYCHIATRY

Dr. Martin specializes in Internal Medicine and Psychiatry and has served as Medical Director of the Adult Sickle Cell PCMH since July 2012.

Meet Dr. Martin: https://www.youtube.com/watch?v=DbfDPY4BjCI

## Christina Abrams, MD

PEDIATRIC HEMATOLOGY

Dr. Abrams specializes in Pediatric Sickle Cell Disease, Adolescent and Young Women's Health in Hematology and Pediatric Thrombosis. Meet Dr. Abrams: https://education.musc.edu/MUSCApps/FacultyDirectory/Abrams-Christina

# Sickle Cell Research: SCDIC

## QUESTIONS AND ANSWERS ABOUT QUALITY OF CARE FOR PEOPLE WITH SICKLE CELL

In 2016, researchers at MUSC joined others around the country to create the Sickle Cell Disease Implementation Consortium (SCDIC), with the goal of improving the health and well being of adolescents and adults with sickle cell disease (SCD).

Their research first focused on asking SCD patients what they need to help improve their routine care. The answers to to those questions informed the second phase of their project, which looked at ways to address the shortcomings in care described in phase I.

So far, the studies include:

- a patient registry of over 2,400 participants that obtains medical information and patient reported outcomes at several points in time
- a study aimed at improving adherence among SCD patients and increasing SCD provider knowledge through the use of two mobile applications
- a study to identify reasons individuals with SCD might not be affiliated with health care
- a study aimed at implementing individualized pain plans with patient and provider electronic health record access for SCD patients in the emergency department
- a needs assessment which used interviews, focus groups, and surveys to determine and address the needs of people with SCD.

**More studies are planned for 2023 and beyond. If you want to get involved, see information below.**

Sickle Cell Patient and college student Alaysia Soles gets routine care at the Pediatric Sickle Cell Clinic at MUSC.

**SCAN HERE FOR RESEARCH RESULTS!**

# Want to be part of SCD research at MUSC?

We are currently recruiting people age 16+ who have SCD to participate our ongoing research. Participation means filling out one survey per year, and you can be paid for your time!

https://tinyurl.com/MUSCSickleCellResearch

Contact us: fostcaro@MUSC.edu or mossjay@musc.edu