

Patient Registration Help Documentation

SC Sickle Cell
Disease Registry

Register at:
<https://www7.gvtsecure.com/scdhec>

SC Sickle Cell Disease Registry

SC Sickle Cell Disease Registry unites patients, caregivers, and health care providers across South Carolina to share knowledge and experience, accelerate progress and advancements in patient care and treatment.

New to the registry?

Register

When you are ready to register – click “Register”.

Registered Participants

username

password



Sign In

Forgot Password?

SC Sickle Cell Patient Registry unites patients, caregivers, and physicians across the South Carolina to share knowledge and experience, accelerate progress and advancements in patient care and treatment.

Are you a patient (someone diagnosed with sickle cell disease) or a caregiver (someone registering on behalf of a patient who has sickle cell disease)?

- I'm a patient
- I'm a caregiver

Step One: The first question helps to identify who is entering patient data. If you are the patient – answer “I’m a patient”, however if you are entering data on behalf of a patient – answer “I’m a caregiver”.

[If you are a caregiver](#) – there are a few personal questions about “YOU” that will be asked, prior to you entering in patient information.

SC Sickle Cell Patient Registry unites patients, caregivers, and physicians across the South Carolina to share knowledge and experience, accelerate progress and advancements in patient care and treatment.

Are you a patient (someone diagnosed with sickle cell disease) or a caregiver (someone registering on behalf of a patient who has sickle cell disease)?

- I'm a patient
- I'm a caregiver

What is your relationship to the patient?

[Select one]

Your First Name

Your Last Name

Informed Consent for Participating in the South Carolina (SC) Sickle Cell Disease Registry

Definitions

For the purpose of this Consent form, "the patient" refers to the person diagnosed with sickle cell disease (SCD). Registry information will be collected on patients who are diagnosed with SCD.

This consent form is for use in a voluntary patient registry involving both adults and minors. Minors do not have the legal capacity to consent to

Step One (continued): If you're a **caregiver** – you will need to answer a few additional questions before proceeding to the "informed consent".

Are you a patient (someone diagnosed with sickle cell disease) or a caregiver (someone registering on behalf of a patient who has sickle cell disease)?

- I'm a patient
 I'm a caregiver

Informed Consent for Participating in the South Carolina (SC) Sickle Cell Disease Registry

Definitions

For the purpose of this Consent form, "the patient" refers to the person diagnosed with sickle cell disease (SCD). Registry information will be collected on patients who are diagnosed with SCD.

This consent form is for use in a voluntary patient registry involving both adults and minors. Minors do not have the legal capacity to consent to their participation. Accordingly, when an individual cannot legally consent to participate, the pronouns "you" and "your" should be read as referring to the patient rather than the parent or guardian who is checking the box at the end of the form to give consent. If you are a minor, your parent or legal guardian must check the box at the end of this form.

Purpose

The purpose of the SC Sickle Cell Disease Registry is to collect, store, and analyze medical and other information from individuals with Sickle Cell Disease (SCD). The data will be used to determine incidence and prevalence of SCD in South Carolina, for clinicians and healthcare professionals to better understand SCD, to help medical professionals make informed treatment decisions, to develop new treatments, and to improve quality of life and patient outcomes. Clinicians and medical professionals studying SCD need accurate information to understand the disease and how it impacts patients over the course of their lives.

The South Carolina General Assembly passed legislation authorizing DHEC to develop and maintain a sickle cell disease voluntary patient registry during the 2021-2022 Legislative Session. Information about the legislation can be found on the [South Carolina Legislature site](#).

There is information about the Registry, including its defined objectives on the landing page of www7.gvtsecure.com/scdhec and on DHEC's website [here](#).

Step Two: Part of the registration process is to read and agree to an **"informed consent"** that describes the nature of this registry. You will have to review the informed consent, no matter if you are a patient or caregiver. Once you have read the information – you can continue to complete the rest of the registry process.

that I want to participate in this registry and any questions I had were answered.

By registering you are agreeing that you are one of the following:

- I am 18 years of age or older and agree to participate in this registry..
- I am the parent or legal guardian of a registrant under the age of 18 and give my permission for my child to take part in this registry.
- I am serving as a witness to this informed consent. The registrant is unable to read this consent form. I confirm that the consent form has been explained to and apparently understood by the registrant and that consent was freely given by the registrant.

Patient's First Name

Patient's Middle Name (Optional)

Patient's Last Name

Email address

Retype Email address

Patient's First Name

Patient's Middle Name (Optional)

Patient's Last Name

Email address

Retype

A: Complete your registration information and click "Register".

Password must have at least 8 characters including at least 1 capital letter and 2 numbers

Retype Password

SHOW PASSWORD

Security Challenge Question

Security Challenge Answer

Security Question: How would you like to receive information in the event you need reset your password?
 Mobile (text message)

 Email

Preferred Method of Survey Reminders
 Email
 Mobile (text message)
 Both

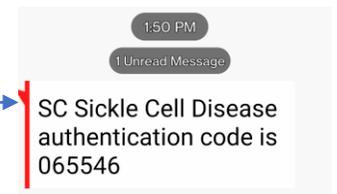
REGISTER



B: Check your email. The system will send a code to your email (or phone) for security purposes. An example code message is below. Just enter in the code and click "Validate" to proceed.

C: You will receive a numeric code by Mobile or Email, depending on the option you chose.

Example text message



Example email message

Your SC Sickle Cell Disease Registry validation key



Copy and paste the following code into the SC Sickle Cell Disease Registry to validate your registration: **121078**

Hello Louis Alcinder!! (000000577)

Please start by telling us who is your primary healthcare provider :

Select your healthcare provider:

(Please select)

Can't find your healthcare provider? Please add below

SAVE



Additional Resources

Downloadable File Example

An example file to download.

[Award.Svg](#)

More Information

18 and Older - Sickle Cell Disease Program

[Find Out More](#)

Press Release

See our press release of the launch of this registry site!

[Check It Out!](#)



Step Four: Congratulations! You have completed the first part of your registration. The last step is for you to identify your healthcare provider from the pre-populated list. If your provider is not on the list - you will be required to provide their First Name, Last Name, and either their clinic name or phone number under "Can't find your healthcare provider? Please add below"

Hello Louis Alcinder!! (000000577)

Please start by telling us who is your primary healthcare provider :

Select your healthcare provider:

(Please select)

(Please select)

- Stephanie Abrams [MUSC Health - Adult Sickle Cell Center]
- Stephanie Andrews [Prisma Health Richland Memorial Sickle Cell Clinic & Infusion Center]
- Alan Anderson [Prisma Health Childrens Hospital - BiLo Charities Children's Cancer Center/Comprehensive Lifespan Sickle Cell Disease Program]
- Shayla Bergmann [MUSC Children's Health Center - Sickle Cell Center]
- Angie Brown [Prisma Health Richland Memorial Sickle Cell Clinic & Infusion Center]
- Tondre Buck [Gibbs Cancer Center & Research Institute]
- Stuart Cramer [Prisma Health Richland Memorial Sickle Cell Clinic & Infusion Center]
- Damon Daniels [Palmetto Health Infusion Center-Columbia]
- Debbie Disco [MUSC Children's Health Center - Sickle Cell Center]
- Stephen Howard Dyar [Bon Secours Hematology & Oncology Practice]
- Tranaka Fuqua [Prisma Health Childrens Hospital - BiLo Charities Children's Cancer Center/Comprehensive Lifespan Sickle Cell Disease Program]
- Annemarie Gault [Beaufort Memorial Hospital Sickle Cell Clinic]
- Asitosh Gor [Carolina Blood and Cancer Care Associates]
- Sherron Jackson [MUSC Children's Health Center - Sickle Cell Center]
- Mary Johnson [MUSC Children's Health Center - Sickle Cell Center]
- Tiffany Johnson [Palmetto Health Infusion Center-Columbia]
- Dwayne Johnson [Test Clinic for Testing HCP Registration]
- Julia Krater [Beaufort Memorial Hospital Sickle Cell Clinic]

Hello Louis Alcinder!! (000000577)

Please start by telling us who is your primary healthcare provider :

Select your healthcare provider:

(Please select)

Can't find your healthcare provider? Please add below

Dr. Paul Jonesby

SAVE

Hello Louis Alcinder!! (000000577)

Current Announcement Message - example for testing purposes.
Testing link to [google](#).



Profile Information



Additional Resources

Downloadable File Example

An example file to download.

[Award.Svg](#)

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Step Five: Once you add your provider on the previous screen - you will be brought to your patient portal. The portal has [Profile Information](#) that is required to be completed (see examples to the right). Once you complete this information, you will be granted access to the remaining forms for completion.

Patient Demographic Information

Date of Birth

mm/dd/yyyy

Gender

- Male
- Female
- Unspecified
- Prefer Not To Answer

Race (Select Which Applies)

(Please select)

Ethnicity

- Hispanic
- NotHispanic
- Prefer Not To Answer

Please select

- Single
- Married
- Divorced
- Widowed
- Other

Address Line 1

Address Line 2

City

State

SOUTH CAROLINA

Zip Code

County

(Please select)

Regarding housing, do you:

Employment and Education

Employment

Full Time

Part Time

Unemployed

Retired

Prefer Not To Answer

Education Level (Please select)

High School Diploma

Some College

Bachelor's Degree

Graduate Degree

Family History

Do you have family members living with Sickle Cell Disease?

Yes

No

Do you have family members living with Sickle Cell Trait?

Yes

No

SAVE

Hello Louis Alcinder!! (000000577)

Update Your Account under Account Preferences Tab as needed.



Profile Information

🏆 Completed! Thank you!



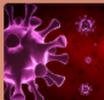
Health History



Disease Assessment



Quality of Health Questionnaire



Covid History



Additional Resources

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Hello Louis Alcinder!! (000000577)

Click the tiles/picture/link below to begin your assessments. You can Save and Close at anytime while completing the assessments.



Profile Information

🏆 Completed! Thank you!



Health History

🏆 Completed! Thank you!

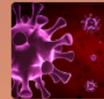


Disease Assessment

🏆 Completed! Thank you!



Quality of Health Questionnaire



Covid History

🏆 Completed! Thank you!



Additional Resources

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[Award.Svg](#)

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[Check It Out!](#)

Step Six: Once you've completed your **Profile Information** – you will see a yellow trophy symbol indicating you have completed that level of information. There are **4 remaining areas** (short forms) that will require your input before you are finished. Note- as each section is completed, you will see the trophy symbol appear next to that section.

Hello Peter Parker!! (000000517)

Update Your Account under Account Preferences Tab as needed.



Profile Information

Completed! Thank you!



Health History

Completed! Thank you!

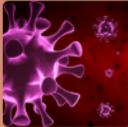


Disease Assessment

Completed! Thank you!



Quality of Health Questionnaire



Covid History



Additional Resources

Announcements

More Information

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Check It Out!

Under **Additional Resources** you will have Announcements posted periodically by the SC Sickle Cell Disease Registry Team, information and resources about sickle cell disease services, and news or media releases as it pertains to your community.

History of the Registry

In the 2015-2016 SC General Assembly, the Sickle Cell Disease Study Committee was authorized. This committee was charged with examining existing services and resources available to children and adults living with sickle cell disease (SCD). Findings from the study committee included the need for greater public awareness about SCD, the need for more and better education about SCD processes, and the need for more funding for SCD programs to improve access to health care in both urban and rural areas of the state. One of the recommendations of the study committee included the need to develop a Sickle Cell State Plan. From this recommendation, the South Carolina Sickle Cell Disease Advocacy Team was brought together in 2017 to develop and implement the South Carolina Sickle Cell Disease State Plan in A Call to Action.

Although the SC Sickle Cell Disease State Plan addressed public awareness and education, health care provider education, access to health care, and funding, there are still gaps in the management of SCD in South Carolina due to lack of providers, lack of education for providers, need for public awareness, and limitations to accessing appropriate care, especially in hospital emergency departments.

In an effort to improve care coordination efforts between the patient, caregivers, and health care providers, the SC General Assembly passed "Rena Grant Sickle Cell Disease Voluntary Patient Registry Act" in the 2021-2022 legislative assembly which directs SC Department of Health and Environmental Control to establish and maintain a sickle cell disease voluntary patient registry.

The South Carolina Sickle Cell Disease Registry will facilitate the collection of data about incidence and the nature of SCD in the state which can be used to educate

Other Resources/Web Pages:

- [About the Registry](#) – This page includes background information on the origination of the SC Sickle Cell Disease Registry.

Resources

These organizations provide some of the following services: genetic counseling, counseling services and community education, emergency client assistance, disease and trait screening, family and individual education and counseling, support groups, and nurse case management.

Local Community Based Organizations and Support Services

Committee on Better Racial Assurance (COBRA)
<http://www.cobraagency70.com/home.html>

James R. Clark Memorial Sickle Cell Foundation
<http://www.jamesrclarksicklecell.org/>

LD Barksdale Sickle Cell Anemia Foundation
<https://www.ldbarksdalese.org/>

Orangeburg Area Sickle Cell Anemia Foundation
www.orangeburgsicklecellfoundation.com

The B Strong Group
<https://thebstronggroup.org/>

DRE 365
[DRE 365 - Facebook](#)

Shanavia's Dream Sickle Cell Clinic
www.sdse.my.canva.site.com

Sickle Cell Lights of Hope
[Sickle Cell Lights of Hope - Facebook](#)

Family Connection of South Carolina, Inc.
www.familyconnectionsc.org

National Organizations

Sickle Cell Disease Association of America (SCDAA)
<https://www.sicklecelldisease.org/>

Other Resources/Web Pages:

- **Resources** – This page contains links to community based organizations, national organizations, and sickle cell centers who provides service and treatment to individuals living with sickle cell disease.

Contact Information

Who do I contact with questions?

If you have questions about the registration process or about participation in the registry, please contact the registry team at sicklecellregistry@dhec.sc.gov. To report concerns about your participation in the registry, you may contact the registry team at 803-898-0784.

Other Resources/Web Pages:

- Contact – This is the [Contact](#) page to reach the SC Sickle Cell Disease Registry Team.

 Patient Profile & Preferences

HOME

Share with your Healthcare Provider

Select your healthcare provider:

Dwayne Johnson [Test Clinic for Testing HCP Registration] ▼

Can't find your healthcare provider? Please add below

SAVE

Patient Information

Email

georgeritaccotest@gmail.com

Patient's First Name

Louis

Patient's Last Name

Alcinder

DOWNLOAD CONSENT FORM

Security Challenge Question

Your Pets Name ▼

Security Challenge Answer

..... 

Preferred Method of Security Authentication

- Email
 Mobile (text message)

(770) 634-0959

Preferred Method for Annual Update Reminders

- Email
 Mobile (text message)
 Both

Preferred Method of Survey Reminders

- Email
 Mobile (text message)
 Both

Other Resources/Web Pages:

- This is the [Account Preferences](#) page. You can come to this page at any time to update your contact information, security validation information, or your password.

 Patient Profile & Preferences

HOME

Share with your Healthcare Provider

Select your healthcare provider:

Dwayne Johnson [Test Clinic for Testing HCP Registration] ▼

Can't find your healthcare provider? Please add below

SAVE

Patient Information

Email

georgeritaccotest@gmail.com

Patient's First Name

Louis

Patient's Last Name

Alcinder

DOWNLOAD CONSENT FORM

Security Challenge Question

Your Pets Name ▼

Security Challenge Answer

..... 

Preferred Method of Security Authentication

- Email
- Mobile (text message)

(770) 634-0959

Preferred Method for Annual Update Reminders

- Email
- Mobile (text message)
- Both

Preferred Method of Survey Reminders

- Email
- Mobile (text message)
- Both

To Log Off or leave the system – please choose **Log Off** to sign out of your session.

It's important to remember to **click on LOG OFF** vs. just closing your browser window to exit.

How to Reset Your Password

SC Sickle Cell Disease Registry

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New to the registry?

Register

Registered Participants

username

password

Sign In

Forgot Password?

SC Sickle Cell
Disease Registry

www7.gvtsecure.com says
Click 'OK' to reset your password

OK

Cancel

SC Sickle Cell Disease Registry

SC Sickle Cell Disease Registry unites patients, caregivers, and health care providers across South Carolina to share knowledge and experience, accelerate progress and advancements in patient care and treatment.

New to the registry?

Register

Registered Participants

geogeritaccotest@gmail.com

password

Sign In

Forgot Password?

Password Reset

Email

geogeritaccotest@gmail.com

The temporary password has been sent.

Please check the spam/junk folder if you do not see an email within 5 minutes.

If you forget your password, click on the Forgot Password link. Enter your email address in the field and click Forgot Password, to request a password reset.