



Sickle Cell Disease Association of America, Inc.

Get Connected Registration Form

Form 1 **APPLICANT INFORMATION**

Full Name:

First *M.I.* *Last*

Address:

Street Address *Apartment/Unit #*

City *State* *ZIP Code*

Date of Birth:

Month/Day/Year

Place of Birth: *(optional)*

City *State* *Country*

Home Phone:

() _____
Mobile Phone: () _____

Email Address:

Race:

- | | | |
|---|--|---|
| <input type="checkbox"/> African-American | <input type="checkbox"/> Alaska Native | <input type="checkbox"/> Asian Indian |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Filipino | <input type="checkbox"/> Guamanian |
| <input type="checkbox"/> Hispanic or Latino | <input type="checkbox"/> Japanese | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Other Asian | <input type="checkbox"/> Other Pacific Islander |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Vietnamese | <input type="checkbox"/> White |
| <input type="checkbox"/> Other | <input type="checkbox"/> Refused | <input type="checkbox"/> Don't Know |

Ethnicity:

- | | | |
|--|---|---|
| <input type="checkbox"/> Aboriginal | <input type="checkbox"/> African | <input type="checkbox"/> African-American |
| <input type="checkbox"/> Alaska Natives | <input type="checkbox"/> Albanian | <input type="checkbox"/> Algerian |
| <input type="checkbox"/> Angolan | <input type="checkbox"/> Appalachian | <input type="checkbox"/> Arab |
| <input type="checkbox"/> Armenian | <input type="checkbox"/> Ashkenzai Jews | <input type="checkbox"/> Asian Indian |
| <input type="checkbox"/> Asian Pacific | <input type="checkbox"/> Assyrians | <input type="checkbox"/> Bangladeshi |
| <input type="checkbox"/> Bi-Racial (2 or more) | <input type="checkbox"/> Black Dutch | <input type="checkbox"/> Black Indians |
| <input type="checkbox"/> Bolivian | <input type="checkbox"/> Brazilian | <input type="checkbox"/> British |

- | | | |
|--|---------------------------------------|--|
| <input type="checkbox"/> Cambodian | <input type="checkbox"/> Canadian | <input type="checkbox"/> Chilean |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Cuban | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> Egyptian | <input type="checkbox"/> European | <input type="checkbox"/> French |
| <input type="checkbox"/> Frisian | <input type="checkbox"/> German | <input type="checkbox"/> Greek |
| <input type="checkbox"/> Haitian | <input type="checkbox"/> Han Chinese | <input type="checkbox"/> Hispanic and Latino |
| <input type="checkbox"/> Indian | <input type="checkbox"/> Indonesian | <input type="checkbox"/> Iranian |
| <input type="checkbox"/> Iraqi | <input type="checkbox"/> Irish | <input type="checkbox"/> Italian |
| <input type="checkbox"/> Jordanian | <input type="checkbox"/> Korean | <input type="checkbox"/> Mexican |
| <input type="checkbox"/> Native American | <input type="checkbox"/> Non-Hispanic | <input type="checkbox"/> Pacific Islander |
| <input type="checkbox"/> Pakistani | <input type="checkbox"/> Palestinian | <input type="checkbox"/> Panamanian |
| <input type="checkbox"/> Portuguese | <input type="checkbox"/> Romanian | <input type="checkbox"/> Russian American |
| <input type="checkbox"/> Whites | <input type="checkbox"/> Other | <input type="checkbox"/> Refused |

Gender:

- | | |
|---------------------------------|-------------------------------|
| <input type="checkbox"/> Female | <input type="checkbox"/> Male |
|---------------------------------|-------------------------------|

Are you a member or affiliated with a local community organization? Yes No

If Yes, which one?

If No, would you like to be affiliated with a local community organization? Yes No

Registrant Agreement SCDAA Get Connected Registry

Please read and make sure you understand the information below before signing this form. In this form the term “you” refers to you or your child.

What is the “Get Connected” Registry?

The “Get Connected” Registry is a patient powered registered designed to create a way patients with sickle cell and sickle cell trait can receive information about current advocacy initiatives, treatments, therapies and research studies.

The “Get Connected” Registry is housed at the headquarters of the Sickle Cell Disease Association of America, Inc.

What is Protected Health Information (PHI)?

PHI is information that can identify you (such as your name, address, telephone number) that relates to your past, present or future health issues. The federal privacy regulations of the Health Insurance Portability & Accountability Act (HIPAA) protect your identifiable health information. If you authorize us to use your information we will protect it as required by the law.

Why Should I Join the “Get Connected” Registry?

Patients who participate in the registry may receive or share information critical to establishing of better health policy and improving in federal funding for those living with sickle cell disease. Participation may also make it possible for researchers to find new treatments, create new research studies, develop new public health policy and work for the improvement of all lives affected by sickle cell disease. By joining the “Get Connected” Registry, you may have the opportunity to contribute to the overall improved and increased access to equitable care.

You have a right to refuse to join the “Get Connected” Registry. If you refuse to join the “Get Connected” Registry it will not affect your health care, the payment for your health care, or your health care benefits.

How Do I Join the “Get Connected” Registry?

To join the “Get Connected” Registry you must first complete the initial Enrollment Form and then click the “I Agree” button at the end of this Consent Form. Upon completion of both the Enrollment and Consent forms you are officially connected. You will then be prompted to complete the remainder of your enrollment through additional forms (which are optional).

The “Get Connected” Registry additional forms ask you for information relevant to your diagnosis, treatment, research participation and health care needs.

What Happens After I Join the “Get Connected” Registry?

The SCDAA Get Connected Committee (GCC) will contact you via your portal with information you requested to include but not limited to: advocacy updates, availability of clinical studies, new treatment progress, results of clinical studies and trials, etc.

How Will My Privacy Be Protected?

The SCDAA GCC understands that your PHI is private. We are committed to keeping your PHI private. Information you enter will be stored in a secure database at the SCDAA Headquarters. No PHI will be given to anyone without your permission.

Others that are affiliated with the SCDAA GCC and may see your PHI include:

- Members of the GCC Privacy Board & Committee
- Get Connected staff in the SCDAA Office of Research & Programs, and/or other SCDAA offices that oversee Get Connected projects
- Community-based SCDAA chapters/members that you give permission to view your information during enrollment if you choose to do so.

No other affiliated entities shall be added to the above list without your expressed permission.

How Can I Be Contacted Directly?

You will be given the option of sharing the information you enter into the “Get Connected” Registry Enrollment Form directly with staff and/or community-based members. If you choose to share your PHI with community-based members:

- the SCDAA GCC will provide your PHI to the groups you select to share your information with.
- you may be contacted directly by the groups you select to share your information with.
- the SCDAA GCC will no longer have control over who has access to your PHI from the standpoint of these members, however all information in the registry will remain protected and private.

How Do I Complete the Enrollment?

By signing this form, you are giving your permission to use and/or share your non-identifiable health information for any and all research, advocacy or informational related purposes. Your authorization to use your non-identifiable health information will not expire unless you stop your enrollment in the "Get Connected" Registry.

What If I Change My Mind and I Want to End My Enrollment?

You can stop your enrollment in the "Get Connected" Registry using links provided in communication you receive from the SCDAAGCC or by contacting the Sickle Cell Disease Association of America, Inc.

What if I Have Questions?

Contact the SCDAAGCC (at GetConnected@sicklecelldisease.org) if you have questions about this form or the "Get Connected" Registry.

By signing this I acknowledge that I have read, understand, and agree to accept the terms of this form.

Signature (*Patient or Parent/Guardian if minor*)

Print Patient Name

Date

1. Please indicate your sickle cell disease phenotype:

- SS S Beta Zero – Thalassemia S Other
 SC S Beta Plus - Thalassemia Not sure what type

2. What was your age at diagnosis?

- At birth (Newborn Screening) Less than 1 year old 1-5 years old
 5-10 years old 11-20 years old 21-30 years old
 31-40 years old 40 years or greater

3. Are you interested in securely storing your diagnostic electrophoresis results? Yes No *(If yes, please upload into the system)*

4. Are you currently receiving Chronic Transfusion Therapy? (regular blood transfusions every 3-6 weeks)?

- Yes No

5. Have you received a Bone Marrow Transplant?

- Yes No

6. Do you currently take Hydroxyurea (Hydrea, Droxia)? (If answer is No complete section and continue to question 8.)

- Yes No

7. How long have you been taking it? (complete section and continue to question 11)

- Less than a year 1-3 years 4-6 years
 7-9 years 10-15 years 16-20 years
 20 years or greater

8. Have you heard of Hydroxyurea? Yes *(continue to question 9)* No *(continue to questions 10)*

9. Have you taken Hydroxyurea before? Yes *(continue to questions 11)* No *(continue to questions 10)*

10. Would you like to know more about Hydroxyurea? Yes No

11. Are you interested in securely storing your red cell antigen phenotype information for safe red cell transfusions?

Yes No *(If Yes, please upload into the system)*

12. Please indicate the following medications you take for pain:

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> Opioids (Morphine,
Hydromorphone (Dilaudid)) | <input type="checkbox"/> Non-steroidal Anti-inflammatory
Agents (Ibuprofen, Motrin) | <input type="checkbox"/> Lyrica |
| <input type="checkbox"/> Codeine | <input type="checkbox"/> Naproxen (Aleve, Naprosyn) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Oxycodone (Percocet) | <input type="checkbox"/> Keturoloc (Torodol) | <input type="checkbox"/> None |
| <input type="checkbox"/> Methadone | <input type="checkbox"/> Acetaminophen (Tylenol) | |

13. If you are taking medication for iron overload, please indicate which:

- Deferasirox (ExJade, Jadenu) Deferrioxamine (Desferal)
 Deferiprone (Ferriprox) Other: _____

14. If you are taking medication for infection prevention, please indicate which:

- Penicillin Erythromycin
 Amoxicillin Other: _____

15. Please indicate any of the following supplements you may take:

- Folic Acid Zinc None
 Vitamin D Vitamin C
 Vitamin A Other: _____

16. Do you currently take blood thinners? Yes No

17. Do you currently take blood pressure medication? Yes No

18. Do you currently take diabetes medication? Yes No

Signature

Date

And by way of this signature, I authorize this information to be entered into the Get Connected Patient registry by Sickle Cell Disease Association of America, Inc.

Form 3**PHYSICIAN AND HEALTH RELATED SERVICES INFORMATION**

1. Do you have a Primary Care Provider (SCD Center, etc.)? Yes No *(If No, continue to 5)*

If Yes, please provide contact information for your physician:

Name:

Address:

Phone:

Email:

2. Do you feel your physician has knowledge about SCD? Yes No

3. Are you happy with the care you receive from this physician? Yes No *(Please provide comments)*

Comments:

4. Would you like to invite your physician to be part of the Get Connected System? Yes No

5. Do you receive treatment from a health care center? Yes No *(If No, continue to 6)*

If Yes, please provide the name of the center and contact information:

Name:

Address:

Phone:

Email:

Is there someone specific you call to make appointments? Yes, please list information No

Name:

Phone:

6. Please list the Emergency Room or Day Hospital you use most frequently.

Name:

City:

State:

7. Do you have a local pharmacy that you use most frequently? Yes, please list information No

Name:

Address:

Phone:

8. Do you have a dentist? Yes, please list information No

If Yes, Would you like to provide their contact information? Yes No

Practice Name:

Name:

Address:

Phone:

10. If you have a primary caregiver at home, please provide their information.

Name:

Address:

Phone:

Email:

Relation (mom, dad, sister, etc.):

11. Have you ever participated in a Clinical Trial? Yes No

12. Are you interested in receiving information on open Clinical Trials? Yes No

13. Are you interested in receiving information on any of the following?

- | | |
|---|---|
| <input type="checkbox"/> Disease self-management | <input type="checkbox"/> Local SCDAA activities |
| <input type="checkbox"/> Health policy | <input type="checkbox"/> National SCDAA |
| <input type="checkbox"/> Summer camps | <input type="checkbox"/> conferences/webinars |
| <input type="checkbox"/> Sickle cell friendly pharmacies in your area | <input type="checkbox"/> Other |

Signature

Date

And by way of this signature, I authorize this information to be entered into the Get Connected Patient registry by Sickle Cell Disease Association of America, Inc.

Information

- 1. Are you interested in being contacted by pharmaceutical companies about clinical trial participation? Yes No
- 2. Are you interested in being contacted by government agencies about healthcare related activities? Yes No
- 3. Have you enrolled in other sickle cell disease registries? Yes, please describe in comments No

Please Describe:

- 4. Are you interested in enrolling in other registries? Yes No

Signature:

Date:

And by way of this signature, I authorize this information to be entered into the Get Connected Patient registry by Sickle Cell Disease Association of America, Inc.

NEWS FEED CATERGORIES

To sign up for different news categories, please check your areas of interest below.

- Sickle cell disease and self-care
- Clinical Trial Updates
- Awareness and advocacy
- Disease research
- Trait research