

Get Connected Registry

What is Get Connected?

The **Get Connected** registry is intended for children and adults with sickle cell disease, their families and healthcare providers, as well as advocacy groups, researchers, and people with sickle cell trait. The platform is a way to connect people with sickle cell disease to resources on healthcare, behavioral health, clinical trials, and more.

Is My Medical Information Safe?

Yes, the platform offers patients a safe way for storing their medical information related to diagnosis and treatment, which should make it easier for patients to navigate through the healthcare system.

What Can I Use Get Connected For?

Get Connected provides patients with access to disease-specific healthcare services and high-quality information about clinical care, research, advocacy and policy issues concerning sickle cell anemia. It is also intended to promote clinical research initiatives on sickle cell disease by getting scientists together with the aim of developing clinical studies based on the needs of sickle cell patients.

How Do I Register?

Registration is very simple, visit https://www4.gvtsecure.com/reg_scdaa/



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Registration Instructions

- 1. Go to www.GetConnectedSCD.org
- 2. Click on the Register button.
- 3. Enter your email address, then click Check.

4. Select how you would like to register: If you have Sickle Cell Disease or Sickle Cell Trait, click on the "Individual with Sickle Cell Disease or trait".

5. Next, choose the group that relates to you. Are you an adult with Sickle cell disease or trait; or a child under 18 yrs with sickle cell disease or trait?

6. Then complete the for all information on this page is required.

7. Under local SCDAA Affiliation, select an answer for Are you a member or affiliated with a local community organization?

- 8. Read and/or Print the Terms and Conditions, then scroll to the bottom.
- 9. Click the Checkbox, I Agree.
- 10. Click on the Join Button to submit your form.

11. After completing the form you should get an email from reg_scdaa@globalvisiontech.com.

12. Follow the prompts in the email to get your temporary password and return to the Get Connected Website.

13. You will now be able to create a permanent password.

14. Now you're almost done with the registration process! Sign-in using your email & new password into your own page.

15. On your Get Connected Page, you can sign-up for updates regarding sickle cell disease & self-care, clinical trial updates, awareness & advocacy, disease & trait research. You can also fill out the remainder of your registry forms.

16. After filling out all of the forms and choosing the updates you wish to receive, you have now completed your Get Connected Registration. You can take the information you've stored on your page with you and update it at your leisure.