



PRESS RELEASE
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Sickle Cell Disease Association of America, Inc. Launches Get Connected
First Patient-Powered Registry for Sickle Cell Disease

BALTIMORE, MD — The Sickle Cell Disease Association of America, Inc. (SCDAA) is officially launching the first patient powered registry for sickle cell disease (SCD) that allows for the *secure* storage of health information that enables patients to better navigate the health care system and to be counted, showing the number of people living with the disease and the significance of this public health issue. On June 19th, World Sickle Cell Day, SCDAA will launch a social media blitz about Get Connected, encouraging individuals to register.

Get Connected is intended for children and adults with SCD and their families, children and adults with sickle cell trait, health care providers, clinical researchers and advocacy organizations. It provides high quality information about clinical care, research and health advocacy issues related to sickle cell disease and sickle cell trait. It also improves access to disease specific health care and serves as a platform for research initiatives generated by the needs of the SCD patient population.

Since 2015, SCDAA has trained its community-based member organizations on Get Connected and the shared measurement system, and has encouraged them to promote the platform in their regions. As of June 5, 2018, 6,128 individuals are enrolled in Get Connected, and 4,984 of those enrolled are patients, 633 are individuals with trait and 511 are non-patients.

“We are very excited to officially launch Get Connected, the first patient powered registry for sickle cell disease, especially on World Sickle Cell Day,” said SCDAA President/CEO Beverley Francis-Gibson. “This database provides a significant benefit for the sickle cell community and for our efforts to share information, resources, and to collect data that can be leveraged for advocacy, research and awareness efforts. We encourage individuals to register today.”

Get Connected has several benefits, including:

- Connects those affected by SCD to high quality resources for information on health care, behavioral health, clinical research, and other resources.
- Establishes a secure network to share information related to clinical care, research, health services, policies, and advocacy.
- Establishes patient-powered registry for secure storage of medical information related to diagnosis and treatment.

To register for Get Connected, visit www.GetConnectedSCD.org.

About the Sickle Cell Disease Association of America, Inc. - Sickle Cell Disease Association of America, Inc.'s mission is: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. Visit: www.sicklecelldisease.org.

About Sickle Cell Disease - Sickle cell disease, an inherited blood disease, causes red blood cells to have a sickle-shape. With their stiffness and unusual shape, blood flow is blocked to different tissues, ultimately damaging them. These red blood cells contain an abnormal type of hemoglobin, hemoglobin S, while normal red blood cells have hemoglobin A. Hemoglobin is important to the body because it helps the body carry oxygen throughout the body. There is currently no universal cure.

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