

ABOUT SCACURE

SCACURE Networks Inc. (hereinafter referred to as SCACURE) was established to address the needs of the Sickle Cell community in Southern Indiana, with strategic plans for growth and expanded partnership in the future into the central and northern regions of the state of Indiana and eventually throughout the Midwest. SCACURE stands for “**Sickle Cell Anemia CURE**” consistent with the organization’s efforts to educate, engage, and empower those affected by Sickle Cell (Disease and Trait) and other hemoglobinopathies.

The initial client base was approximately 350 people with the Sickle Cell Trait or Disease, in 7 (seven) of the 24 Southern-regional counties who have been without support services for newborn screening, Sickle Cell Trait (SCT), Sickle Cell Disease (SCD), and other hemoglobinopathies counseling and education. That client base has increased to more than 1,000 over the past eight years, with an increased coverage to 35 counties in Southern Indiana and the growing population of Haitian immigrants and others from the Caribbean and Southeastern US region.

Our services and support programs continue to drive much-needed education and training enabling the afflicted families to be proactive and better manage their health and wellness in the wake of these hemoglobin disorders, in partnership with local healthcare providers, school administrators and staff, organizations such as the Red Cross of Evansville and others in the community who will also benefit from our educational programs and services.

Key objectives of SCACURE, Inc. in addressing the needs of ALL Stakeholders in the lifecycle of these hemoglobin disorders that have been and that will continue to be fulfilled through age-appropriate, target-audience driven content, including

- Newborn Screening follow-up on presumptive positive SCT clients. Ensuring the parents and the infant are connected with the provider; provider awareness, and referral for follow-up screening. Providing counseling on the basics of Sickle Cell disease, trait, and other hemoglobinopathies. Offering educational workshops and opportunities for on-going support and engagement with a broad network for support.
- Bridging the knowledge gaps for healthcare professionals through education, training, and outreach programs. Prompt and proper treatment based upon foundational knowledge about the disease can make the difference between life and death as indicated by those who have had direct experiences when going to an emergency room and facility where medical professionals’ awareness and knowledge are lacking.
- Engaging the broader community where emergent populations of those affected by Sickle Cell are un-served or under-served. SCACURE continues to drive increased awareness about SCT, SCD, and other hemoglobinopathies and provide outreach to generate more advocates for quality of life for those directly afflicted by Sickle Cell; and to increase the population of blood donors to support the needs of Sickle Cell patients for life-saving blood transfusion.

SCACURE is proud to join other agencies in the Sickle Cell arena, its leadership brings over eighteen years of experience as an advocate for awareness, education, and proactive prevention having built relationships with medical staff at Riley Hospital, Social Services staff at Riley hospital, and volunteering/engaging partnerships with the medical and social services staff at the Indiana Hemophilia & Thrombosis Clinic (IHTC) for client engagement and various studies, as well as being a voice for panels led by the Indiana State Department of Health and the IHTC to improve emergency room service levels and patient care. Direct work with more than 500 clients over the past ten years, served by the support group of the Martin Center Sickle Cell Initiative, the North Central Sickle Cell Initiative, and the conglomerate organization: the Indiana Sickle Cell Consortium; has provided a foundational knowledge and framework about the real issues facing families with newborns, older

children, and younger and older adults with Sickle Cell Disease; as well as athletes and other individuals with the Sickle Cell Trait. Through these experiences and interactions, and more importantly, the networks created, SCACURE continues to replicate such networks and engagement to serve identified clients in the Southern Region of Indiana and leverage any prior efforts and accomplishments of other agencies in Indiana.

SCACURE brings a perspective to the social service provisions with a deeply-rooted educational and performance improvement background and ability to work collaboratively across local borders and various stakeholder groups. One significant gap in services across Indiana has been the on-going engagement and education to truly empower the Sickle Cell and hemoglobinopathies communities.

As part of a comprehensive workplan, SCACURE delivers a variety of programs and services to address the growing numbers of at-risk populations with more children, adults, families, and communities enduring the complications resulting from Sickle Cell disease, trait, and other hemoglobinopathies. These programs have been based in the communities and localities where the target audience groups live and work.

The programs bring together small communities with common needs together in small-group forums for awareness, education, follow-up, and follow through. This includes parental programs, programs for other caregivers; and programs for teens, youth, working adults pursuing entrepreneurship, medical professionals, community advocates, and related interest/public-service groups who engage with the Sickle Cell communities.

SCACURE's mission is broad outreach, thus engaging partners across multiple facilities within the community; Programs are offered in schools and universities, medical office conference spaces, libraries and even restaurants for example as part of outreach efforts. Additionally, SCACURE has established partnerships to empower parents and youth, and working adults leveraging the subject-matter experts and professionals as primary facilitators for key awareness, educational, training and outreach programs and services. This has enabled SCACURE to manage the curriculum design and development by audience group and keep the most up-to-date expertise in the forefront of the target audience populations being served. SCACURE has patterned programs after the "Schools without Borders" concept by being primarily decentralized. Experience working with global customers for more than 30 years supports the likelihood of success, having managed distance and decentralized learning at Fortune 500 organizations such as Eli Lilly and Company, Roche Diagnostics, and Cummins Inc.

SCACURE has been able to address the awareness, educational, training and development, and newborn screening follow-up needs throughout Southern Indiana Region and, in some cases, neighboring states such as Illinois and Kentucky, Partnerships with the Indiana Sickle Cell Consortium peer organizations and the Center for Disease Control, as well as the Indiana State Department of Health enable on-going program and service assessment, collaboration, and best-practice sharing for continuous improvement and to ensure the needs are being met with the greatest quality support and service. Growth plans post-pandemic era will be driven solely by the demand and needs of those served and supported in this new way of living and working.

SCACURE has consulted with various medical professionals in the hematology, psychology, and internal medicine fields through the years and also remained current on Sickle Cell related matters through organizations such as the Sickle Cell Disease Association of Medicine. SCACURE has also consulted with a specialist in obstetrics who has a history of providing care in high-risk pregnancies, including women with Sickle Cell Disease and Trait or other hemoglobinopathies. This physician is located in close proximity to the SCACURE home office.

These medical professionals have been invaluable, contributing their expertise for the cause. Their professional guidance, along with SCACURE's founder as lead advocate and educator who serves as the President and Program Director for the organization. With the retirement of the long-supporting Client Services Director, there has been opportunity to engage new resources who are living with Sickle Cell Trait and Disease, have the

ability to share their life journey, and support the organization's Newborn Screening and educational events at local conferences and key projects. Countless other professionals have donated their time to offer programs and services to the client base in Southern Indiana and beyond. Resources have expended anywhere from 5 to 20 hours per week to serve the small Southern Indiana and surrounding populations.

SCACURE's approach to keeping the client as key focus, at the center of everything, and obtaining feedback throughout the program and service deliveries has enabled continuous improvement and provided a foundation for future organizational redesign and effectiveness and ensure the best quality programs and services possible. These efforts, in addition to an on-going focus on professional development to maintain and/or enhance the skill levels and capabilities of the SCACURE staff and partners, will be the foundation for a sustainable organization.

To date, most programming has been offered at no cost. Some of the partnerships, for example, patient identification and tracking with the Martin Center Sickle Cell initiative were at nominal cost based on grant provisions, with a fee of approximately \$20/hour to cover independent resources at a cost comparative to a temporary administrative employee. Additionally, costs for newborn screening sub-grantee work, as determined by the Indiana Hemophilia and Thrombosis Clinic have been based on a per patient processed rate of \$78/initial screening of newborns with families and physicians; and \$45/follow-up contact with families and physicians.

Looking ahead to 2021-2022 programs will shift to more online, with an increased social media presence. Student volunteers in the media will be the primary resource for services with some oversight for website management from a professional to be provided minimal compensation on a per/project basis. This will enable SCACURE to cultivate talent in the Sickle Cell community and those seeking to become Entrepreneurs. It's a demonstrative way to increase outreach, engagement, and empowerment of those served.

SCACURE has been able to pilot entrepreneurial support seeing a client, *Andre's BBQ and Seafood* from grant-development support through funding and service launch. This is an untapped space of support for those working adults with Sickle Cell Disease who have difficulty holding gainful employment due to illness and absenteeism. This work enables them to leverage their passion and natural talents, obtain funding to become a self-supporting entrepreneur and build a solid business with supporting personnel who can keep the business going for a few days or a few weeks should illness befall them. This practice of support and empowerment to clients will be more formalized in the coming year with a zero-cost, total volunteer model to grow capability in this population of adults.

The second program offering SCACURE has been researching and planning for launch in Q3 2022 is that of Financial Independence and Life Sustainability for those graduating high school and entering into college or the workforce. The basis for this program is an at-home Finance course designed by Dave Ramsey's Financial Peace organization, but with some minor modifications to include key concepts like managing Sickle Cell care and self-advocacy balanced with financial responsibility. High School Financial courses are lacking, and young people are entering college or starting life without the basic knowledge of creating and managing a budget or wealth building.

The third program offering to be piloted in the timeframe of late Q4 2021 – Q1 2022 is that of Senior Care and Support for those with Sickle Cell Disease. While there are senior support programs, those that have a focus on Sickle Cell patient care and enablement are virtually non-existent. There are pockets of knowledge and expertise, but nothing substantial. Partnering with Seniors who have Sickle Cell to better understand the needs will enable SCACURE to do a rapid program pilot in the Evansville area.

Other than the Newborn Screening program and other grant and sub-grantee opportunities that allocate available funds, SCACURE will remain as much as possible, a zero-cost, community-based, client-driven

organization. Organization resources, direct and indirect headcount will continue to be deployed on a part-time basis or increased timing as dictated by shifts in the population of Southern Indiana. In 2020-2021 SCACURE saw an increased immigrant population from the Caribbean which increased the numbers of newborns with Sickle Cell Trait and other hemoglobin types by approximately 20% over prior-year averages. Engagement costs were minimal in 2020 due to the pandemic, but a gradual increase is expected going into year-end 2021 and early 2022.

A handful of part-time resources will be needed to further the vision for these programs and services. Most will be volunteers, though SCACURE anticipates leveraging internships for those going into the social services and educational space to be foundational for program development and delivery. The President and Program Director will continue to lead the business while identifying viable candidates to land headcount for succession planning.