



Our Mission: In concordance with the mission of The Sickle Cell Disease Association of America; “to advocate for and enhance our membership’s ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease.”

History: Beginning in March 2009 research was conducted by Mary Bentley LaMar on existing organizations, services and medical resources in New Jersey pertaining to individuals and families who experience sickle cell disease. Agencies, health care professionals and medical centers dedicated to providing health care for those affected by sickle cell disease were consulted. In addition, a review of the literature was conducted and online material related to sickle cell disease services in the State of New Jersey was assessed.

It was clear that in New Jersey there are many dedicated health care professionals who provide much needed care for the sickle cell community, especially the pediatric population; however, more help is still needed. In addition, the adult sickle cell community does not have adequate community based support for their medical and non medical needs. After consulting with community based sickle cell disease organizations and health care providers in New Jersey, Illinois, Michigan, Missouri, California and Pennsylvania, the National Sickle Cell Disease Association of America (SCDAA), and individuals in the State of New Jersey interested in improving conditions for individuals with sickle cell disease, it was clear there was a need for a community based sickle cell organization in New Jersey.

As a result, Mary enlisted the help of Ansley W. LaMar, Vallerie Cleveland, Deborah Wilson, Beverly Lucas and Darlene Young to serve on the Board of Directors and Connie McGhee Esq; to serve as legal counsel, to found The Sickle Cell Association of New Jersey, Inc., affectionately referred to as SCANJ (pronounced “scan-juh”). Processes were put in place to adhere to the standards of The Sickle Cell Disease Association of America. **SCANJ was incorporated on September 1, 2009.** A media advisory was sent announcing its establishment including an invitation for the public to attend a special dedication of the organization on September 27, 2009 at the Shiloh Baptist Church in Newark, New Jersey.

Led by Founder and Executive Director, Mary Bentley LaMar, SCANJ’s first program was held January 30, 2010, an educational Meet and Greet was held at the Newark Public Library Main Branch and the organization’s mission was shared with the attendees. Participants were educated on sickle cell disease and sickle cell trait and were made aware of services available in the state of New Jersey for people with sickle cell disease. A panel discussion including individuals with sickle cell disease, medical professionals and sickle cell disease advocates was a highlight of the program. A follow up survey for the Meet and Greet, to assess its effectiveness and to guide improvement was sent to the participants and the feedback was positive.

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EIN# 80-0474935

Since that first program, SCANJ has hit the ground running with programs and services to further its mission. We've participated in the Sickle Cell Disease Association of America Advocacy Day in our nation's capitol. Mary Bentley LaMar, Darlene Young and Olga Barnwell from SCANJ along with sickle cell advocates from throughout the country and staff members from the SCDAAC convened on Capitol Hill. They met to advocate for increased funding for the Sickle Cell Treatment Act and other sickle cell programs with New Jersey congressman Donald Payne. They also met with staff members from Senator Lautenberg's, Congressman Robert Melendez and Congressman Albio Sire's offices, to inform them about the needs of individuals in New Jersey affected by sickle cell disease and to ask for their support. The New Jersey legislators expressed support for the sickle cell treatment act programs.

Other Key programs since being established:

- ✓ The New Jersey Sickle Cell Poster Child and Teen Spokesperson Program
- ✓ Chronic Disease Self Management Workshops and Peer Leader Training for adults with sickle cell disease or other chronic conditions.
- ✓ Educational programs such as *A Sickle Cellabration*, Workshops & Presentations, Speakers Bureau, Health Fairs, SCD brochures and educational materials distributed
- ✓ Inspirational programs such as *The December Holiday Party*, *The Thanks For Giving Concert* and *Kente Carpet Movie Premiers*
- ✓ SCANJ Road Trips for families affected by Sickle Cell Disease to attend symposiums such as the James B. Herrick Symposium on Sickle Cell Disease at NIH, SCDAAC Conventions and other scientific conferences.
- ✓ *Say It Loud* Awareness Program
- ✓ Creating a Blood Drive Task Force
- ✓ *The 24 Seven Line Dance Marathon* Fundraiser

SCANJ has partnerships with area hospitals, medical providers and advocacy organizations in the furtherance of our mission. In addition we work in concert with the SCDAAC in accommodating requests. One such example was to help a New Jersey family assist three of their Haitian relatives with sickle cell disease to escape the ravages of the Haiti earthquake and receive medical care in New Jersey. This request forced our newly formed agency to kick into high gear coordinating with other agencies, medical providers, legal advisors and government entities to assist the family. It resulted in finding funding for travel expenses, legal advice and social services support for the family.

SCANJ colors are "kente" yellow and red, representing a heritage of hope for the blood.

Our motto is "SCANJ equals faith with good works for sickle cell disease."

We are able to serve the public good thanks to funding from grants, sponsorships, and most of all generous contributions from the general public.

Visit www.sicklecellnewjersey.org or call at 973 482-9070 for more information

Mailing Address P.O. Box 9501, Newark, NJ 07104

Mary Bentley LaMar, Executive Director

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