Giving New Voice
An SCDAA Overview.....

Working Together to Change Lives

By Sonja L. Banks
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Sickle Cell Disease Association of America, Inc.
The Sickle Cell Disease Association of America, Inc. (SCDAA) serves as the nation’s largest member-based organization working full time on a national level to resolve issues surrounding sickle cell disease.
Our Mission

"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."
Our Members

“MO’s are the foundation to both SCDAA and the SCD community.”

- Community based organizations designed to serve individuals and families in their respective communities by offering program and outreach services.
- Assist clients with finding quality healthcare
- Maintain databases of individuals and families that have been served over the years
- Community Outreach
- Educate local communities
SCDAA Members are classified in the following categories:

• DIRECT PATIENT CARE SERVICES
• SUPPORT SERVICES
• ADVOCACY SERVICES
Giving New Voice

SCDAA Current Initiatives
Key Focus Areas

- CBO CAPACITY BUILDING
- LEGISLATIVE ADVOCACY
- AWARENESS & OUTREACH
- PATIENT CARE & RESEARCH
Community – Based Capacity Building

➢ Launch SCDAA Leadership & Training Academy
  ○ Professional Training, Organizational Capacity Training, Program Training

➢ Launched the National SCD Community Health Worker (CHW) training program
  ◦ CHW Core Competencies
  ◦ 7 week program
  ◦ 40 hours of Field Work
  ◦ SCD Focus
  ◦ National Exam

➢ SCDAA Mini Grant Program
Legislative Advocacy

- Re-introducing Re-Authorization of Sickle Cell Treatment Act - Bill H.R. 1807 in the House
  *Treatment Centers, Surveillance, Clinical Research and Transition programs*

- Recently Testified before Energy and Commerce Health Subcommittee
Clinical Trial Awareness Initiatives
- National Top Ladies Clinical Trial Awareness Campaign
- 10 City Town Hall Tour

Bone Marrow Donation and Donor Education
- Partnership with Be The Match
- Co-Branding Materials re: BMT & Donor Drives
- Booth in a Box Program with CBO’s

National Blood Drive Campaign
- Delta Sigma Theta National Drive Program

Hydroxyurea Education
- CHW Education Program through HRSA Grant
Research & Programs

➢ HRSA Newborn Screening NBO

• Goals:
  1. Partner with Community-Based Organizations
  2. Locate Non-active Patients
  3. Provide Care Coordination & Medical Home Assistance
  4. Educate on Hydroxyurea
  5. Develop Shared Measurement System for Data Collection
Research & Programs

HRSA Newborn Screening NBO

• Progress:

1. (25) CBO Awardees throughout (5) Regions

2. 82 CHW’s certified, trained & hired
   ▪ 70% Pass rate
   ▪ 82% Retention rate

3. 5,918 Non-active Patients enrolled for care coordination services

4. Approximately 3,000 successfully placed in Medical Homes or provided with Medical Home referrals

5. 4,124 Educated on Hydroxyurea
Research & Programs

➢ Get Connected Patient Powered Registry

2015 Launched 1st and only SCD Patient Powered Registry

• Design for children and adults living with sickle cell disease to store medical information related to diagnosis, treatment and potential cure

• Created to establish a network of children, adults and families living with sickle cell disease, SCDAA member organizations, health care providers and other community-based organizations to distribute information related to clinical care, research, health services, health policy and health care advocacy
PCORI Patient Engagement Program

Goals:

1. Address the active integration of patient, stakeholder, and research communities in the research process.

2. Develop an informed patient community and encourage participation in patient-centered outcomes research.
PCORI Patient Engagement Program

Progress:

1. Completed a National PCOR Peer Curriculum
2. Established the 1st PCOR Peer Facilitator Program for Patients and Parents
3. Trained through Pilot (12) Peer Facilitators
4. By October 2017 total of 25 facilitators to be trained
5. Facilitators to educate over 2500 peers (patients/parents) by June 2018
Special Events

June 19, 2017
SCD World Day Global Twitter Party

August 26, 2017
National Sickle Cell Walk with the Stars

September 2017
SCD Legislative Briefing & Luncheon on the Hill

October 25 – 28, 2017
45th Annual Convention – Atlanta, GA
“Coming together is a beginning. Keeping together is progress. Working together is success.”

Henry Ford