Giving New Voice
An SCDAA Overview…..

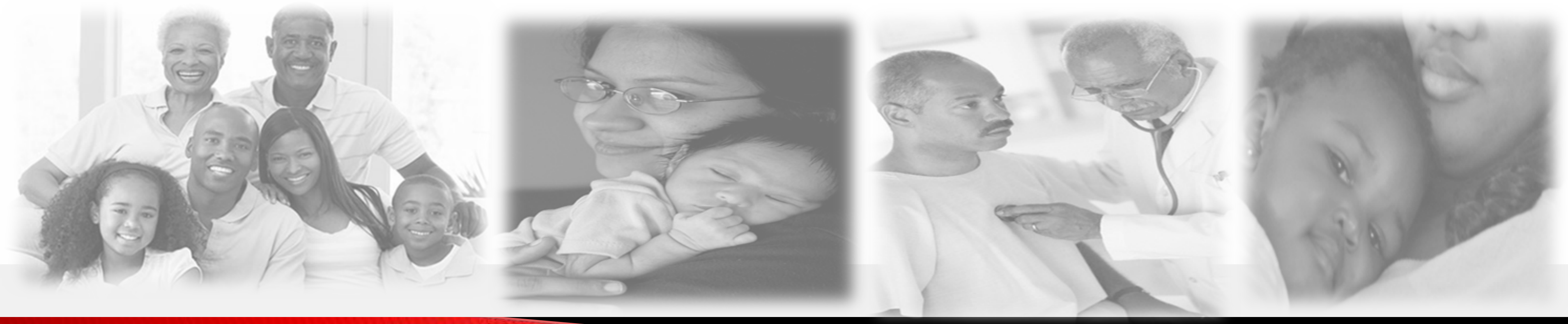
"Break The Sickle Cycle"

By: Beverley Francis-Gibson
President & CEO
Sickle Cell Disease Association of America, Inc.

The Sickle Cell Disease Association of America, Inc. (SCDAA) serves as the nation's only volunteer organization working full time on a national level to resolve issues surrounding sickle cell disease.

Our Mission

"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."



Our Members

"MO's are the foundation to both SCDAA and the SCD community."

- Forty-five (45) 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

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SCDAA Members are classified in the following categories:

- DIRECT PATIENT CARE SERVICES
- SUPPORT SERVICES
- ADVOCACY SERVICES

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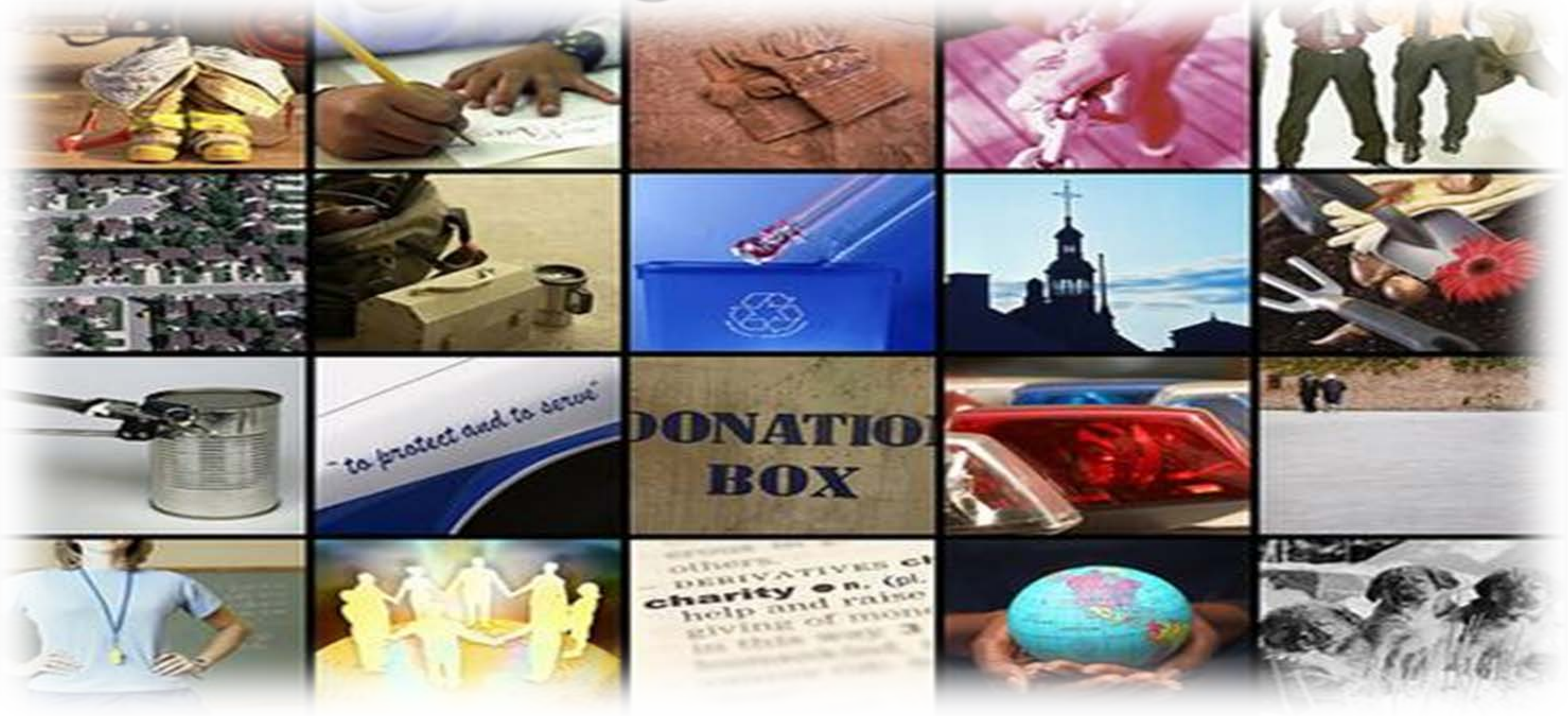

SCDAA Current Initiatives

2018 – 2019 Key Focus Areas

- AWARENESS & OUTREACH
- LEGISLATIVE ADVOCACY
- CBO CAPACITY BUILDING
- KEY PARTNERSHIPS AND COLLABORATIONS
- TREATMENT & RESEARCH

Community – Based Capacity Building

- **SCDAA Leadership & Training Academy**
  - Professional Training
  - Organizational Capacity Training
  - Program Training
- **National SCD Community Health Worker (CHW) training program**
- **National Sickle Cell Advocacy Network (NSCAN)**

Legislative Advocacy

- **Introduced the Re-Authorization of Sickle Cell Treatment Act Companion Bill to Bill H.R. 2410 in the House**

  Treatment Centers, Surveillance, Clinical Research and Transition programs

Partnership with ASH, MAP and others organizations to support legislation in support of individuals and families living and coping with sickle cell disease.

Awareness & Outreach

- Clinical Trial Awareness Initiatives
- Bone Marrow Donation and Donor Education
- National Blood Drive Campaign
- Hydroxyurea Education
- National Public Awareness Campaigns

Research & Programs

- **HRSA Newborn Screening Coordinating Center**
  - Establish a national infrastructure to ensure diagnosed individuals receive follow-up services: counseling, education materials and access to a medical home
- **Get Connected Patient Powered Registry-to date 6,190 individuals are registered**

Purpose of "Get Connected"….

- 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
- Establish a registry for children and adults living with sickle cell disease to store medical information related to diagnosis, treatment and potential cure
- Establish a network of providers that are educated about the unique health care and psychosocial needs of children and adults living with sickle cell disease
- Connect children and adults with sickle cell disease to high quality resources for information on health care including behavioral health, clinical research and ancillary health care resources
- Establish a network to support clinical research through community-based research navigators

Blood Disorders – Basic and Translational Research

Moderator: Beverley Francis-Gibson, Sickle Cell Disease Association of America

Speakers

Merlin Crossley, University of South Wales

Sivaprakash Ramalingam, Institute of Genomics and Integrative Biology

Matthew Porteus, Stanford University

Junjiu Huang, Sun Yat-sen University

Vence L. Bonhan, National Human Genome Institute