



American Society of Hematology  
Helping hematologists conquer blood diseases worldwide

A horizontal band featuring a microscopic image of blood cells, showing various red and white blood cells with distinct nuclei and cytoplasm.

## Building a Relationship With Community Based Organizations

**Derek Robertson** – The Maryland Sickle Cell Disease Association

**Mary Brown** – Sickle Cell Disease Foundation

# Presenter: Mary Brown



Sickle Cell Disease Research Foundation—Established in 1957

Sickle Cell Disease Foundation Celebrating 65 years of service

- Mission statement has been revised over the years but the focus remains the same
- Strong relationships with Medical Institutions and Health Care Providers
- Clinical and CBO roles and responsibilities—setting the tone
- Building programs with clinical and CBO components
  - Demonstrate a mutual/respectful working relationship
- Guiding Star: “Patients First”



# CBOs and Clinical Partners Advocating for Change



Dr. Diane Nugent and Mary Brown



The Patient Experience



Educating Elected Officials



Assembly member, Mike Gipson



# SCDF Program Connection to NCSCC



**Aim of NCSCC:**  
Improve the rate of mortality among individuals with SCD in California.

**Specific Outcomes:**

1. Network of SCD Centers
2. Workforce Expansion
3. Surveillance and Monitoring
4. Outreach and Education



**SCDF Mission:**

**The Sickle Cell Disease Foundation provides life-enhancing education, services, and programs for individuals living with sickle cell disease.** We broaden public awareness, deliver effective advocacy initiatives, and promote innovative therapies to ultimately find a cure.



**Health Education**

Development and Implementation of Penelope  
Technical Assistance for Outreach and Education  
CHW Training  
Data Monitoring

**Newborn Screening**

Counseling/Services  
Expansion of NBS follow-up services to CBO/Clinic sites  
Data Monitoring  
Hemoglobin Trait Follow-up Training Program

**Operations**

Onboarding of new staff (CHWs, SCDF staff, and consultants)  
Management of subawards  
Creation of policies and procedures

**Family Programs and Services**

Development and Implementation of Penelope  
Expansion of Transition Care services to CBO/Clinic sites  
CHW Training  
Data Monitoring  
Camp Crescent Moon/SC Crew

CHW, community healthcare worker; NBS, newborn screening.



American Society of Hematology

# Networking California for Sickle Cell Care

Comprehensive care for adults—transition from pediatric SCD centers to multidisciplinary team based care and preventive care in full partnership with community-based organizations



American Society of Hematology

# Presenter: Derek Robertson



## Maryland Sickle Cell Disease Association (MSCDA):

- MSCDA is a small all-volunteer organization formed in 2006 whose mission is to improve the quality of life of those affected by sickle cell disease by promoting advocacy, education, research, and excellent health care delivery
- Financial support, transportation support, legislative advocacy, and raising awareness about SCD

## Derek Robertson:

- President–MSCDA
- Over 30 years experience working in health care: Patient advocacy, patient care, industry, and provider advocacy
- Parent of three boys–two of whom have SCD





# MSCDA Conference and Advocacy Day (2019)



# Philosophy of Care and the Value of the CBO in the Delivery of Care

- Patient centered care should tap into all aspects of an individual's needs—clinical and non-clinical
- Consistent with comprehensive care model of care
- CBOs can tap into non-clinical aspects of persons living with SCD—transportation, financial hardships, support groups, etc
- Build communication between patient and providers





# Establishing a CBO Connection

- Check for the existence of a CBO in your area: SCDAAs website for a list of chapters, or do a Google search
- Talk to your patients
- If no CBO exists, use the opportunity to help form one
- Offer to host the initial meeting but don't take control
- Encourage patients and families to get involved. Provide some guidance and look for the leaders.
- Be consistent
- Try to find a location outside of the hospital for meetings



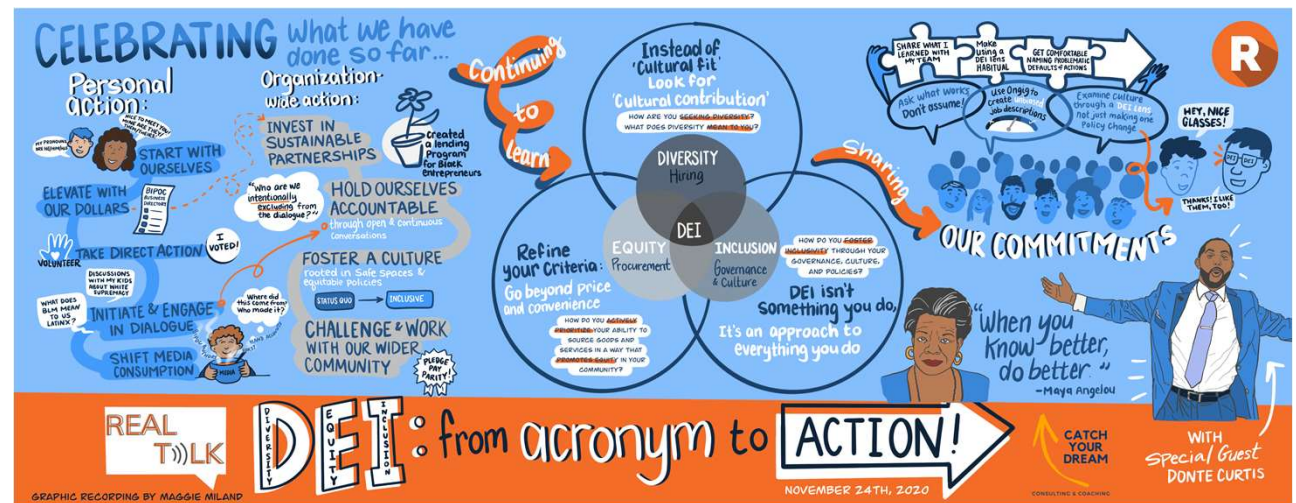
# Establishing a CBO Connection

- If CBO does exist, be the first to engage
- Ask to meet with CBO leadership. Often this could be an individual.
- Open a line of communication
  - Find out what they need
  - Listen
  - Have a mechanism to address challenges
- Explain your treatment philosophy especially as it relates to pain management
- Discuss the establishment of a Community Advisory Board (CAB)



# Communication

- Between institution, patient, and community
- Challenges when communication breaks down
- Addressing delicate issues
  - Racism
  - Diversity
  - Equity
  - Inclusion
  - Bias incidence response process



# Embedding CBO/CHW in the Clinical Care Team

- Opportunities
  - Offer a platform for a support group (in person or virtual)
  - Promote the support group
  - Establish a MOU to allow CBO/CHWs to participate in clinics
  - Include CBO in grant opportunities
  - Begin regular meetings for Committee of SCD Center and CBO (monthly or quarterly)
- Challenges
- Addressing the social determinates of care—Who is responsible?

MOU, memorandum of understanding.



American Society of Hematology

# Contact Information

- Mary E. Brown, President and CEO, Sickle Cell Disease Foundation  
3602 Inland Empire Blvd., Suite C315, Ontario, CA 91764  
Phone: (909) 743-5226, Fax: (909) 743-5227  
Los Angeles: (310) 693-0247  
Visit us at: [www.scdfc.org](http://www.scdfc.org)
- Derek Robertson, President, Maryland Sickle Cell Disease Association  
8775 Centre Park Dr., #701, Columbia, MD 21045  
Phone: (410) 465-4822 (Voicemail)  
[mscdainfo@verizon.net](mailto:mscdainfo@verizon.net)  
Visit us at: [www.marylandsicklecelldisease.org](http://www.marylandsicklecelldisease.org)

