

# California Sickle Cell State Planning Initiative Face-to-Face Meeting

27 January 2018 Sacramento, CA



Sickle Cell Care Coordination Initiative



**UCDAVIS**  
**HEALTH**





# CALIFORNIA SICKLE CELL STATE PLANNING INITIATIVE

# PATIENT / FAMILY ADVOCATE VOICE

Mary E Brown

President & CEO

Sickle Cell Disease Foundation of California



# The Nation's Oldest Community Sickle Cell Advocacy Organization

60 years ago the Sickle Cell Disease Research Foundation (now the Sickle Cell Disease Foundation of California-SCDFC) was incorporated to:

- Raise awareness
- Educate the community
- ***Advocate*** for individuals and families
- Provide research awards to local investigators

***Every Board Member and Staff are ADVOCATES***

# YOUR CONCERNS HAVE BEEN HEARD BUT...

- ◆ We do not speak with one voice
- ◆ We do not have a consistent message
- ◆ We do not have funding for legislative involvement and
- ◆ We tend to work in silos



# Progress Has Been Made....

- ◆ The Pacific Sickle Cell Regional Collaborative has opened opportunities for new partnerships
- ◆ Collaborating with the Center for Inherited Blood Disorders and UCSF Benioff Children's Hospitals has opened doors for the sickle cell community
- ◆ Our collaborative has brought your issues and concerns to our State Government Partners
- ◆ We are offering more provider education opportunities
- ◆ We have opened Adult Sickle Cell Clinics in Orange, Los Angeles and are focused on opening clinics in Riverside, the Antelope Valley and the High Desert.

# Successful Outcomes of this Meeting



Discuss Our Ideas



Plan the Work Ahead



All contribute

# Our Future Looks Bright



- ◆ We will speak with one **Voice**
- ◆ We will develop a **single message and**
- ◆ Will will build new partnerships
- ◆ The State of California will recognize the needs of the sickle cell community and support our efforts