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Newborn screening data for sickle cell disease in California and Georgia, 2004-2016: implications for health interventions

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Background and Objectives

- The Sickle Cell Data Collection (SCDC) program is a population-based, longitudinal surveillance system for sickle cell disease (SCD) that was designed to collect information from multiple data sources, including newborn screening (NBS).
- The SCDC programs in California and Georgia analyzed their NBS data to describe the incidence, demographics, and location of newborns with SCD in the two states.
- These findings may be used to impact health care policies in ways that improve health outcomes and health care access for individuals with SCD.

Methods

- Data on newborns with confirmed SCD born in California or Georgia during 2004 through 2016 were reported to SCDC by the state NBS programs.
- An analysis of sex, race, SCD genotype, and county of residence identified temporal changes in the SCD populations.

Results – Figure 1

- There were 1,165 babies (annual mean = 90 babies) with SCD born in California and 2,025 babies (annual mean = 156 babies) with SCD born in Georgia during 2004 through 2016.
 - 47% (California) and 49% (Georgia) of babies were female
 - 83% (California) and 94% (Georgia) of babies were black or African American
 - Across both states, 56-60% of babies had hemoglobin S/S or S/β⁰ thalassemia; 28-30% had hemoglobin S/C; 8-10% had hemoglobin S/β⁺ thalassemia; and the remainder had other or unknown SCD genotype.

Figures

Figure 1: Sickle cell disease (SCD) genotype

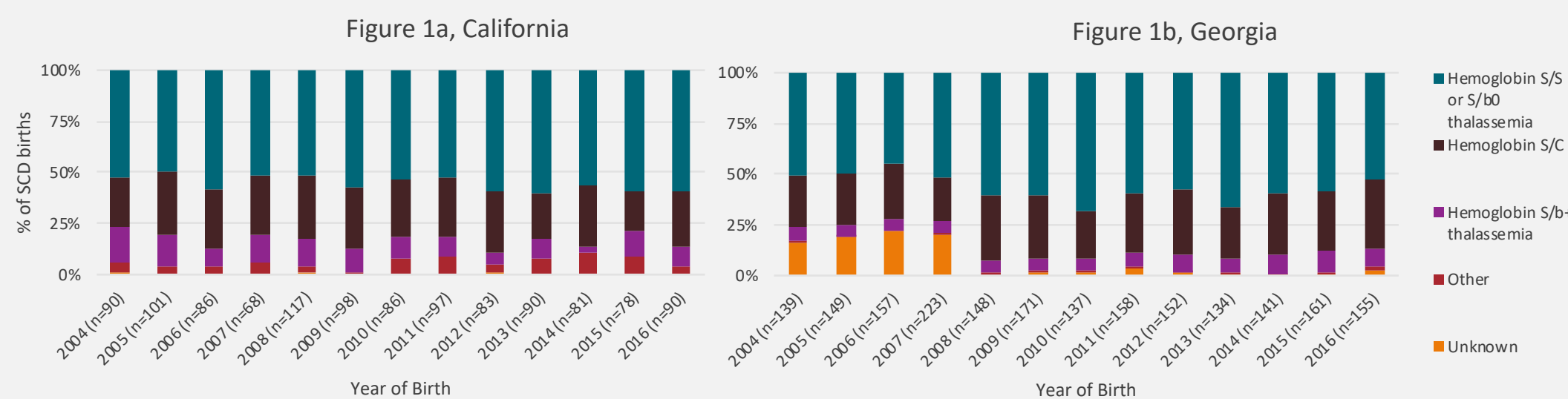


Figure 2: Counties with the highest number of SCD births

Figure 2a: California, 2005-2009

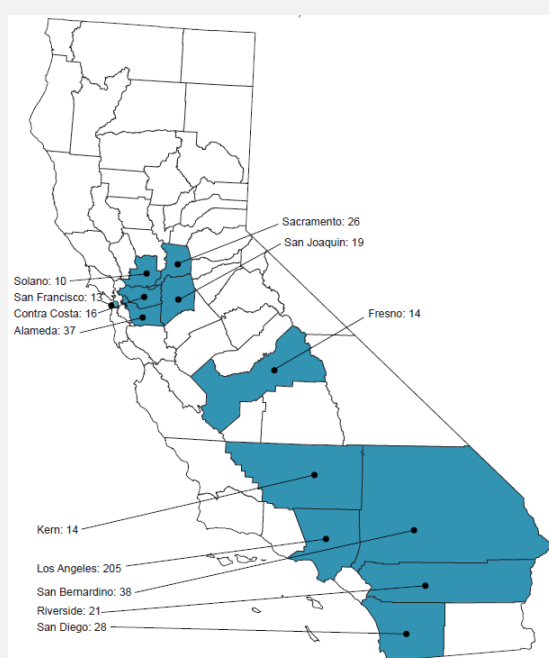


Figure 2b: California, 2010-2014

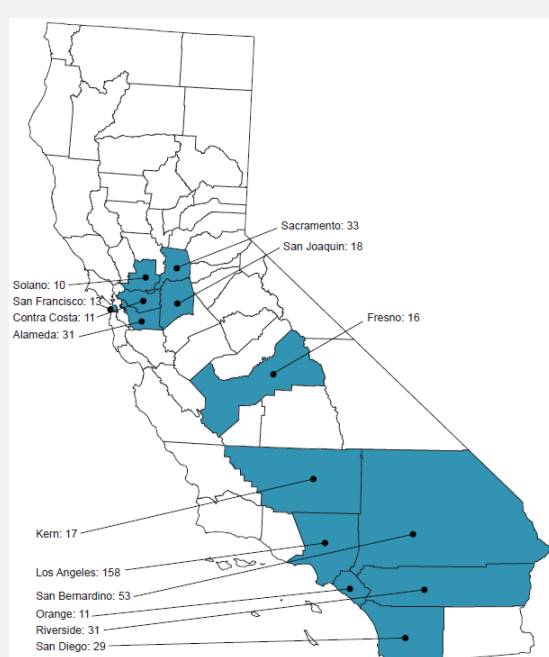


Figure 2c: Georgia, 2005-2009

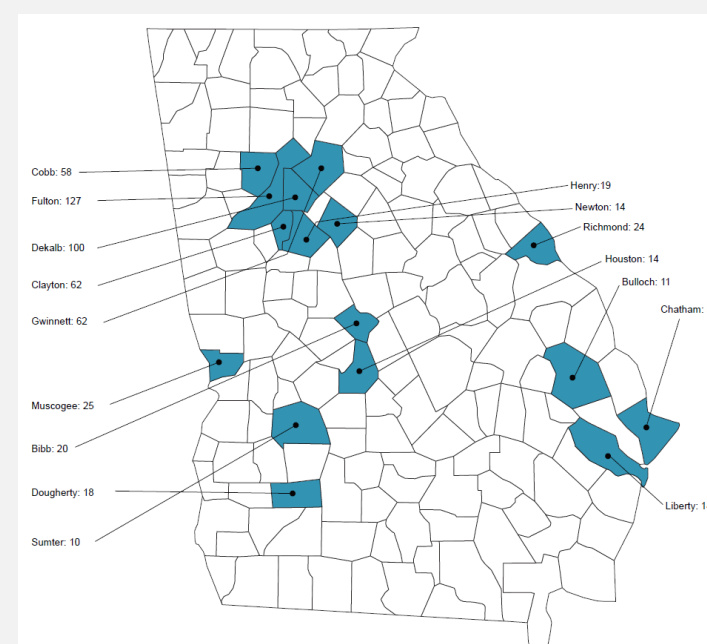
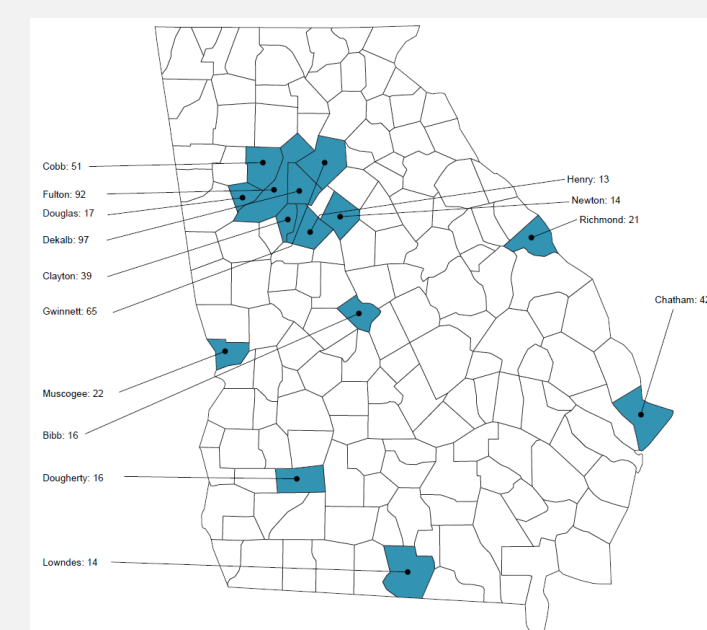


Figure 2d: Georgia, 2010-2014



Results – Figure 2

- In California (Figures 2a-b):
 - Approximately 50% of babies lived in two counties: Los Angeles and San Bernardino
 - Los Angeles County had the highest number of babies born with SCD across the years, but this number declined by 33% from 2005-2009 to 2010-2014.
- In Georgia (Figures 2c-d):
 - Approximately 50% of babies lived in six counties: Fulton, DeKalb, Clayton, Gwinnett, Cobb, and Chatham
 - Fulton County had the highest number of births during 2005-2009 (n=127), but DeKalb County had the highest number of births during 2009-2014 (n=97)

Conclusions

- Data collected through the SCDC program can be used to identify the locations that are most in need of resources to benefit the SCD communities, such as knowledgeable health care providers, specialty care centers, and hospital and emergency facilities.
- These data are critical for understanding changes in epidemiology to identify opportunities for targeted SCD interventions such as:
 - workforce development,
 - patient education, and
 - care across the lifespan.

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