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GEORGIA PHRESH FINDINGS

Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies

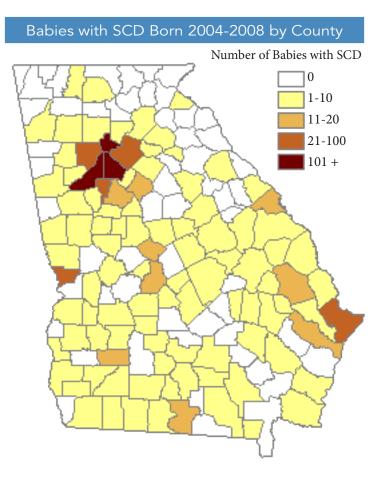
May 2014

Incidence and Migration

Universal newborn screening programs that test for particular medical conditions at birth have made it easier to estimate statewide incidence (number of newly diagnosed cases in a population) of sickle cell disease (SCD) for children born in the United States. However, using newborn screening data to estimate prevalence (total number of cases in a population) is imprecise because these programs have been in place for fewer than 20 years, and the average lifespan for individuals with SCD has increased dramatically over that time. In addition, movement of individuals into and out of Georgia from other states and countries influences state prevalence rates of SCD.

We estimated Georgia's 1-year and 5-year incidence of SCD using the state's newborn screening data, identifying 828 babies born from 2004 through 2008 who had positive screening tests for the disease. This equates to 1 out of every 880 babies born in Georgia during the five-year study period. Among black or African American babies, the rate was approximately 1 in 295. SCD births occurred in over 100 of Georgia's 159 counties during the study period (see map).

Georgia's SCD incidence is shown in Table 1 in comparison to that of other states participating in the RuSH surveillance project. State rates vary by overall population demographics. Georgia's SCD incidence as a proportion of all births is the birbest of these five states. Its incidence area



all births is the highest of these five states. Its incidence among black or African American births is second to New York's.

Table 1. SCD Births in Five States, 2004-2008						
SCD incidence among	GA	NY	NC	CA	MI	
- All births: 1 of every:	880	1,259	1,435	5,644	2,496	
- Black/African American births: 1 of every:	295	260	360	452	467	
SCD babies who are black or African American	97%	89%	95%	89%	96%	



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While we have no data source that identifies individuals moving into the state who have SCD, we can estimate the percentage of young children with SCD living in Georgia during our five-year study period who were born in other states or countries. These children are included in our data if they visited one of Georgia's comprehensive sickle cell centers; were admitted to an emergency department or hospital in Georgia for SCD complications and used an in-state address; or had a medical visit for SCD paid by one of Georgia's public insurance plans from 2004-2008. By matching our confirmed and probable cases of SCD whose birth dates are in the study period with Georgia birth certificates and newborn screening records for the same time period, we developed an estimate of in-migration.



We found that 8 percent of the confirmed SCD cases and 10 percent of the confirmed or probable SCD cases born in this time period had no matching birth certificate or newborn screening record. This suggests that 8 to 10 percent of Georgia's young children with sickle cell disease moved into the state after birth.

By comparison, 10% of California's confirmed SCD cases were not linked to newborn screening records; and North Carolina's newborn screening follow-up program identified 14% of confirmed cases and 16% of confirmed or probable cases who were not born in that state. It should be noted that North Carolina's sickle cell disease surveillance system is considerably more robust than Georgia's.

Table 2. Children With SCD Born 2004-2008 Without a Matching In-State Birth Certificate or Newborn Screening Record				
	Confirmed SCD cases	Confirmed or probable SCD cases		
Georgia	8%	10%		
North Carolina	14%	16%		
California	10%	Not reported		

Public health leaders, health care providers, and advocates for sickle cell patients in Georgia can benefit from understanding incidence and patterns of migration into the state by persons with SCD. This information can help them target outreach and treatment programs to communities with high rates of the disease and migration from high-prevalence areas outside of Georgia.

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