

Using Multiple Data Sets to Build a Surveillance System for Hemoglobinopathies: *Early Lessons from Georgia*

Georgia RuSH Collaborative*

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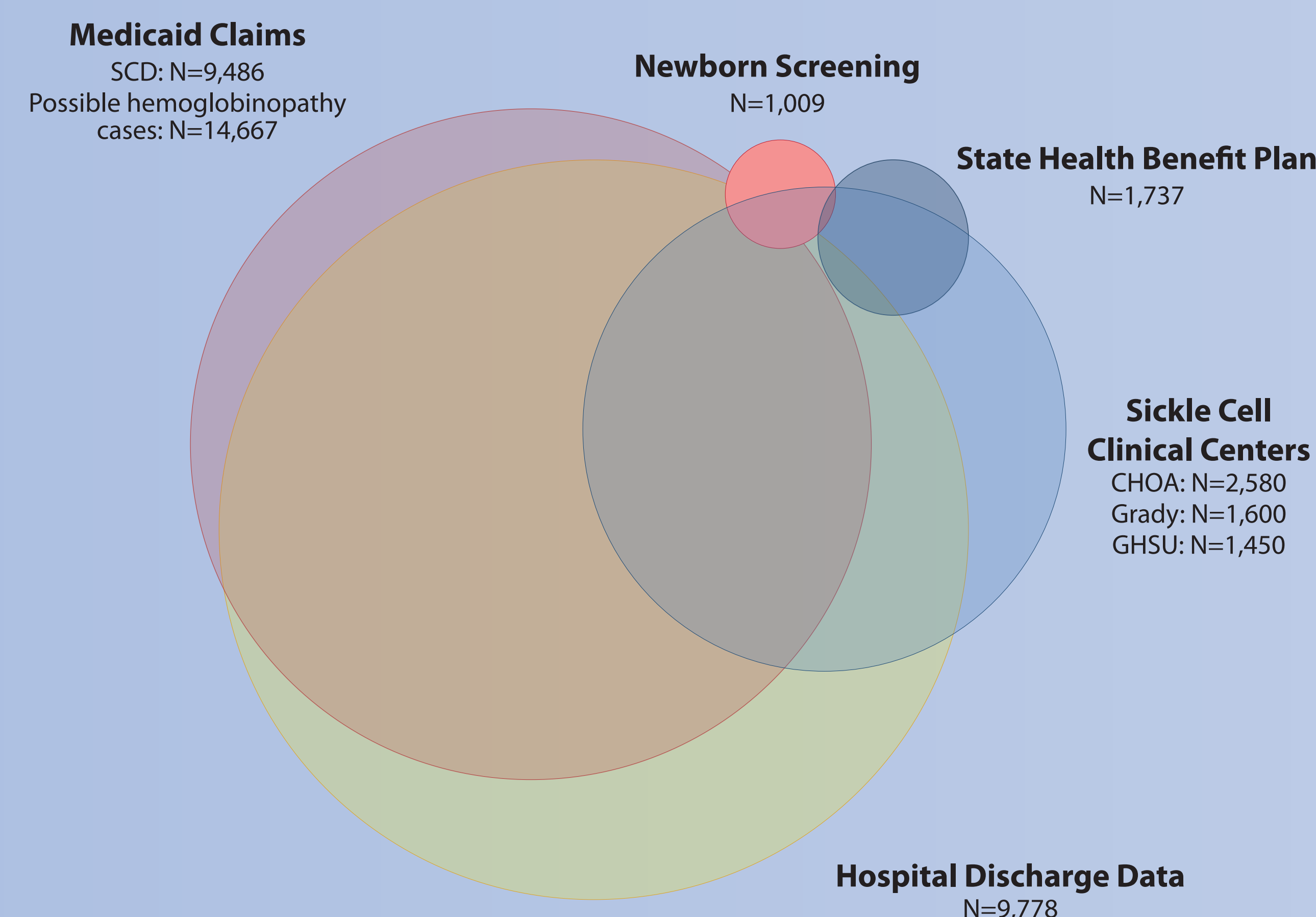
BACKGROUND

Though the total number of individuals with hemoglobinopathies in Georgia is uncertain, it is known that Georgia ranks among the top states in sickle cell disease prevalence. Estimates range from as low as 4,981 to as high as 8,427. Along with six other states, Georgia participated in the two-year Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project. **Objectives:** To determine the annual incidence and five-year prevalence (2004-2008) of hemoglobinopathies in Georgia and to describe the demographics of the populations living with these disorders.

METHODS

Potential cases are identified from five sources: (1) the state newborn screening program (NBS); (2) the Georgia hospital discharge file, which includes most in-patient and emergency room visits in the state; (3) the Grady, CHOA and GHSU health systems, including all outpatient visits; (4) the State Medicaid and CHIP programs; and (5) the State Health Benefit Plan (SHBP). Laboratory screening and confirmatory results, coupled with clinical expertise, are used to confirm cases from NBS, Grady and GHSU data. ICD-9 and CPT codes are used to identify probable and possible cases from additional administrative datasets. Individual datasets are examined to produce preliminary geographic estimates of prevalence and to judge the potential overlap of cases prior to merging all datasets into one surveillance system.

Figure 1: Georgia RuSH project case-finding data sets



RESULTS

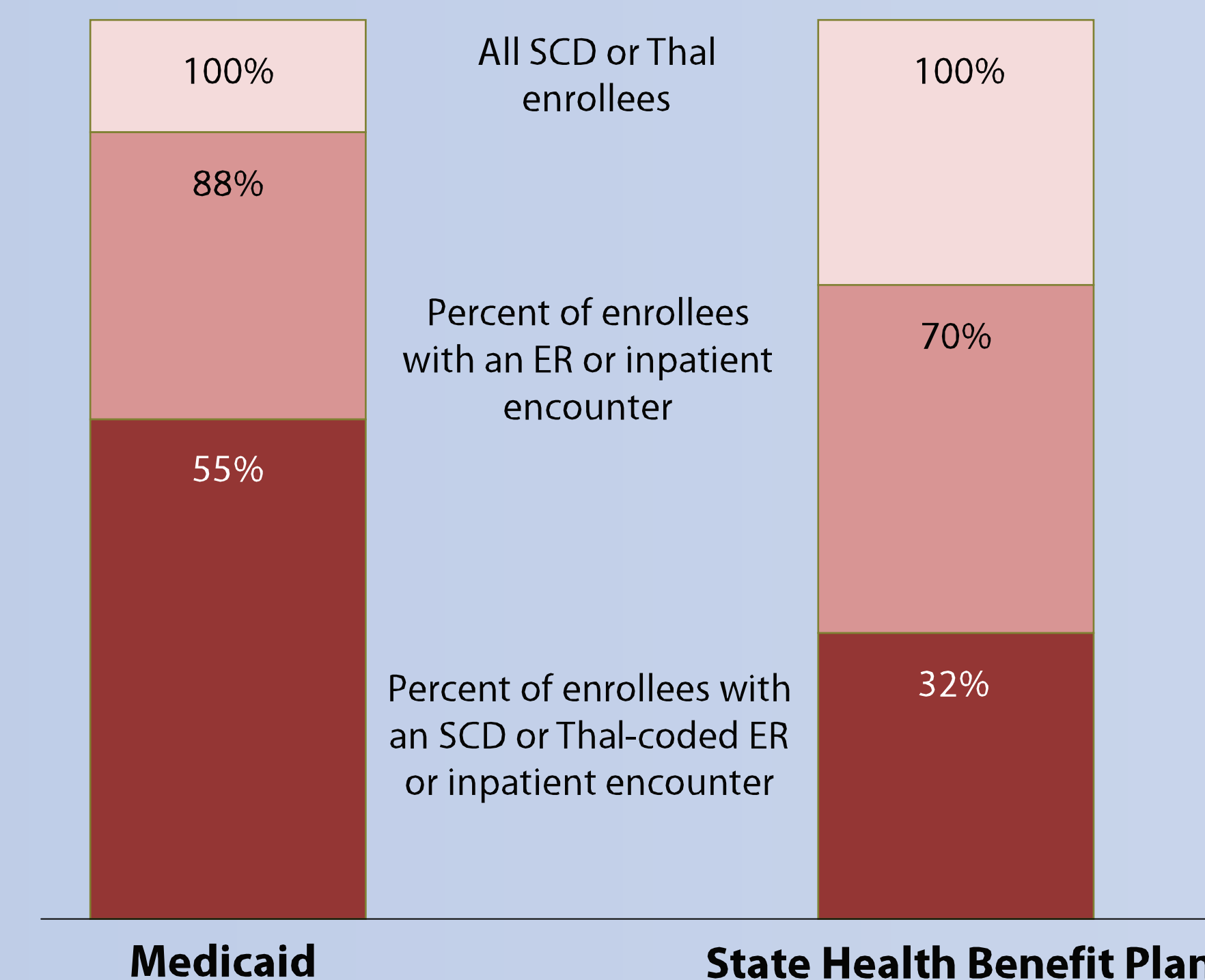
From 2004 through 2008, 1,009 newborns screened positive for a hemoglobin disorder in Georgia. During that same time period, CHOA treated approximately 2,580 pediatric patients with a hemoglobin disorder, and Grady and GHSU treated approximately 1,600 and 1,450 patients, respectively. Medicaid and CHIP programs paid claims for approximately 14,667 enrollees with a hemoglobinopathy-associated medical encounter, while the SHBP covered such services for 1,737 enrollees. Lastly, close to 9,778 individuals were treated in a Georgia emergency room or hospital for a hemoglobinopathy. (Figure 1) We estimate that up to 47 percent of the 9,778 individuals identified through state hospital discharge data may also be present in one of the three hospital systems' data. (Figure 2)

Figure 2: Clinic Patient/Hospital Discharge Count Overlap, 2004-2008

Facility/System	Individuals Seen	Percent of Disease Population Seen
Grady Memorial Hospital (includes Hughes Spalding)	2,059	21%
Children's Healthcare of Atlanta (Egleston & Scottish Rite)	1,896	19%
Georgia Health Sciences University	709	7%
Total disease population per hospital discharge data	9,778	47% max

As well, 55 percent of the Medicaid/CHIP patients and 32 percent of the SHBP patients likely overlap with the hospital discharge file. However, 88 percent of Medicaid enrollees and 70 percent of SHBP enrollees ever coded with a hemoglobinopathy had a hospitalization or ER visit from 2004 to 2008. (Figure 3)

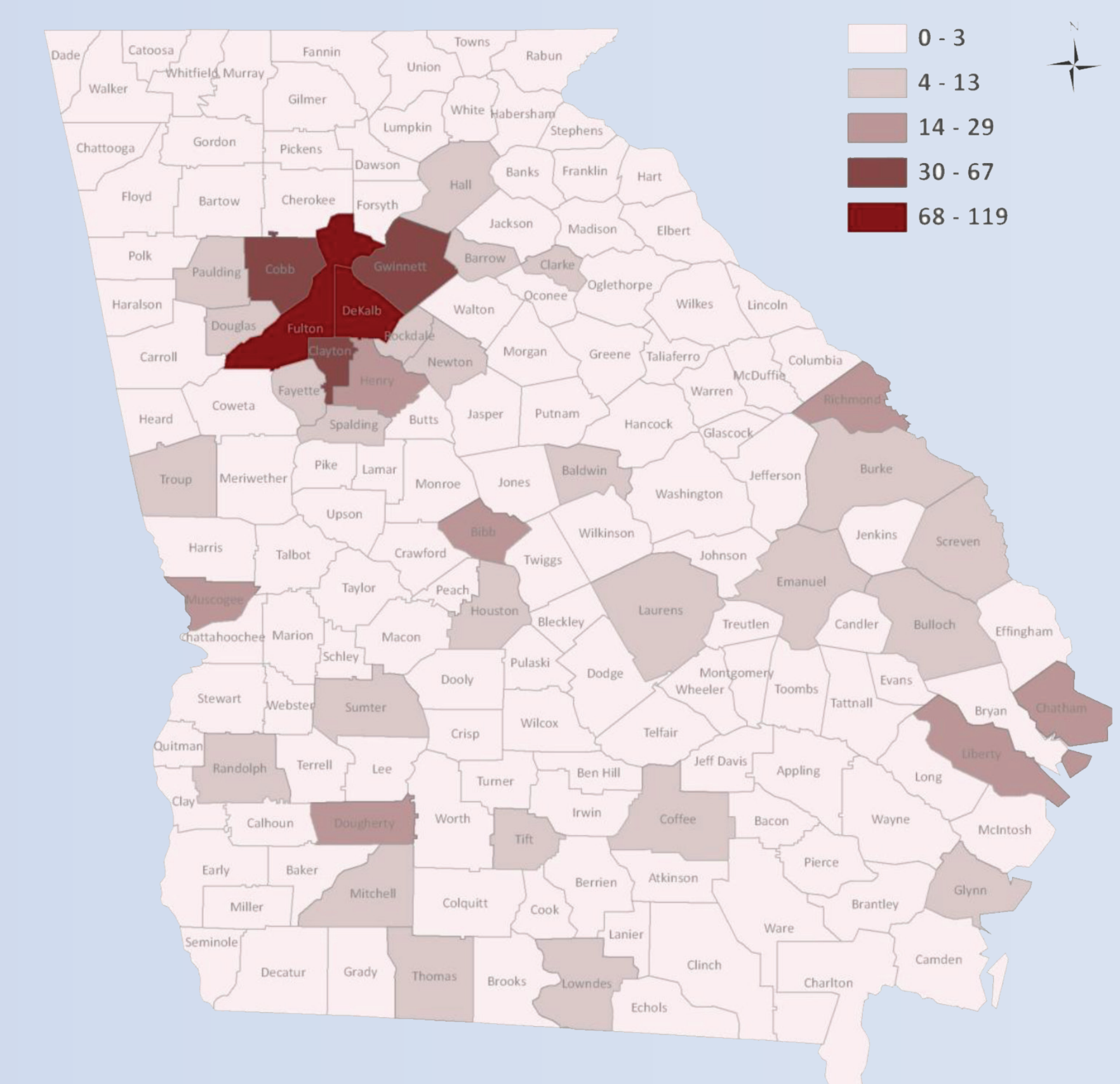
Figure 3: Overlap between Health Insurance Claims data and Georgia Hospital Discharge Data



Close to 90 percent of the newborns identified through NBS are estimated to be followed by one of the three hospital systems.

Using newborn screening data from 2004 through 2008 (Figure 4), we identified the counties with the highest number of incident cases. Most cases are found in the five metro Atlanta counties (Fulton, DeKalb, Cobb, Gwinnett and Clayton) as well as the smaller metropolitan areas in South and Southeastern Georgia.

Figure 4: Georgia newborns screening positive for sickle cell disease, January 2004 through December 2008



CONCLUSION AND IMPLICATIONS

Early outcomes from the Georgia RuSH project have allowed us to identify areas of the state to focus hemoglobinopathy outreach efforts. Further progress will allow us to answer programmatic, policy and outreach questions specific to Georgia, and aid the development of educational materials for providers, policy-makers and legislators. Lessons learned can be shared with other states interested in developing hemoglobinopathy surveillance systems.

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