SUPPLEMENTARY MATERIAL 1: Current participating clinical sites in California and Georgia

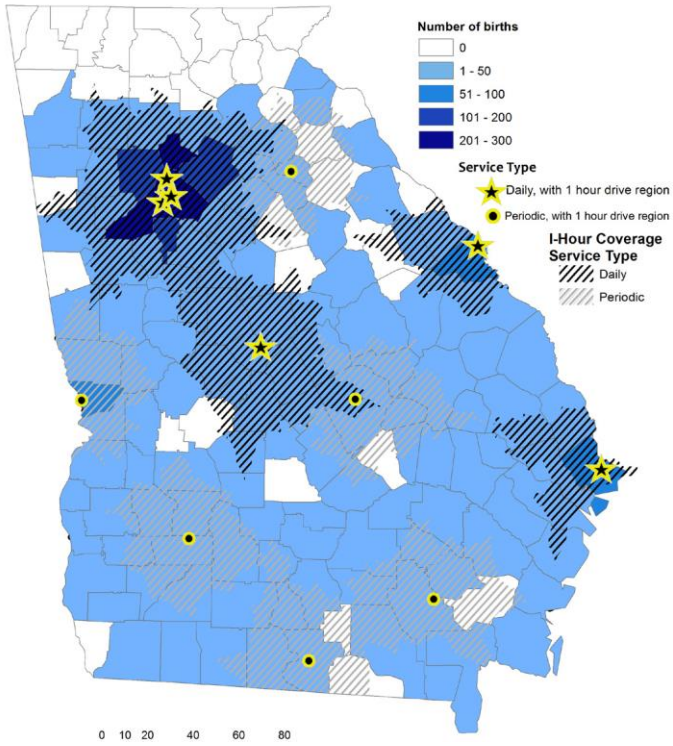
To date California has nine (9) participating clinical sites:

1. University of California San Francisco Zuckerberg General Hospital
2. University of California San Francisco Benioff Children's Hospital Oakland, Stanford
3. University/Lucille Packard Children's Hospital
4. University of California Davis Medical Center
5. Children's Hospital Orange County
6. Center for Inherited Blood Disorders
7. Children's Hospital Los Angeles
8. University of California San Diego Rady Children's Hospital
9. Valley Children's Hospital.

To date Georgia has four (4) participating clinical sites:

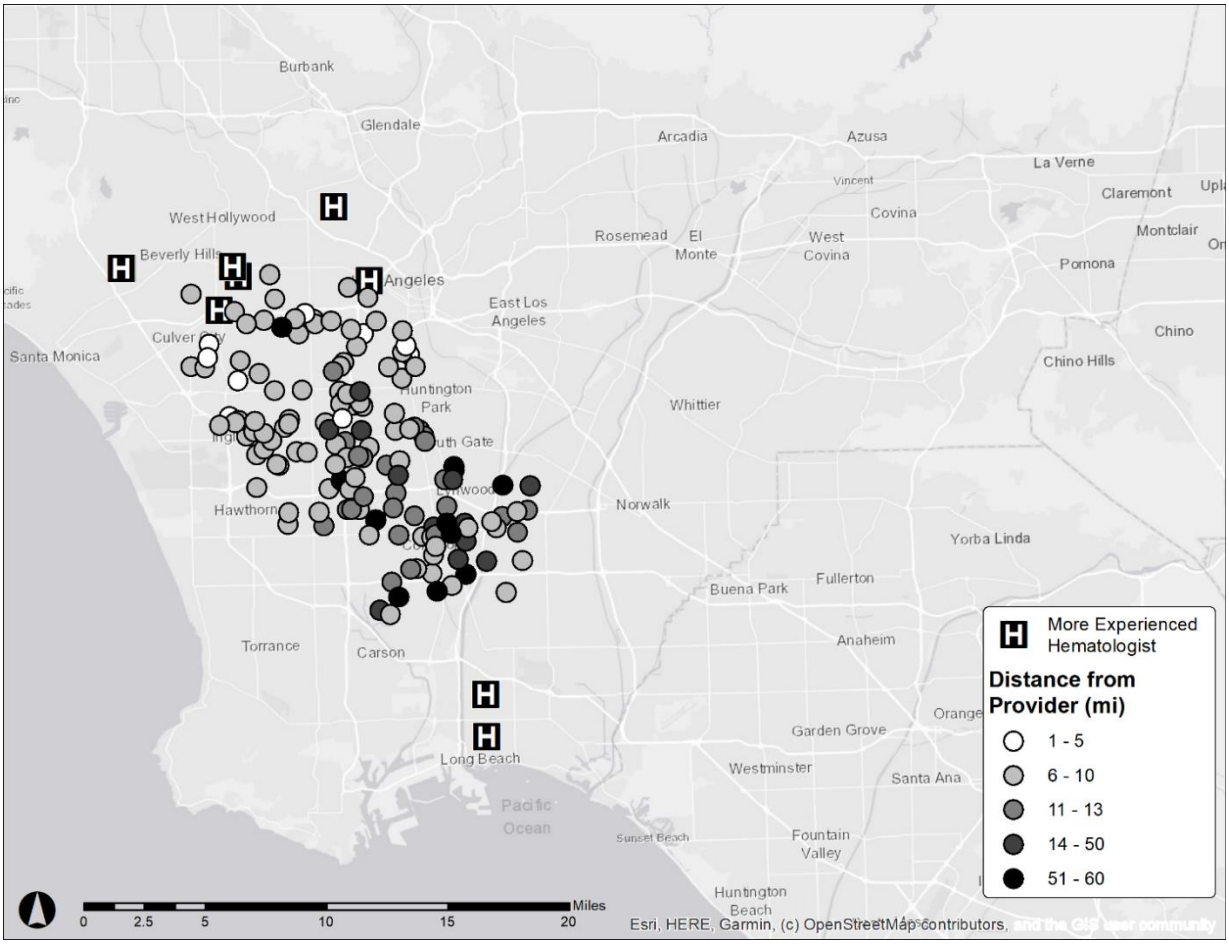
1. Georgia Comprehensive Sickle Cell Center at Grady Memorial Hospital
2. Sickle Cell Disease Program at Children's Healthcare of Atlanta
3. Augusta University Sickle Cell Center
4. Memorial Health Dwaine and Cynthia Willett Children's Hospital of Savannah

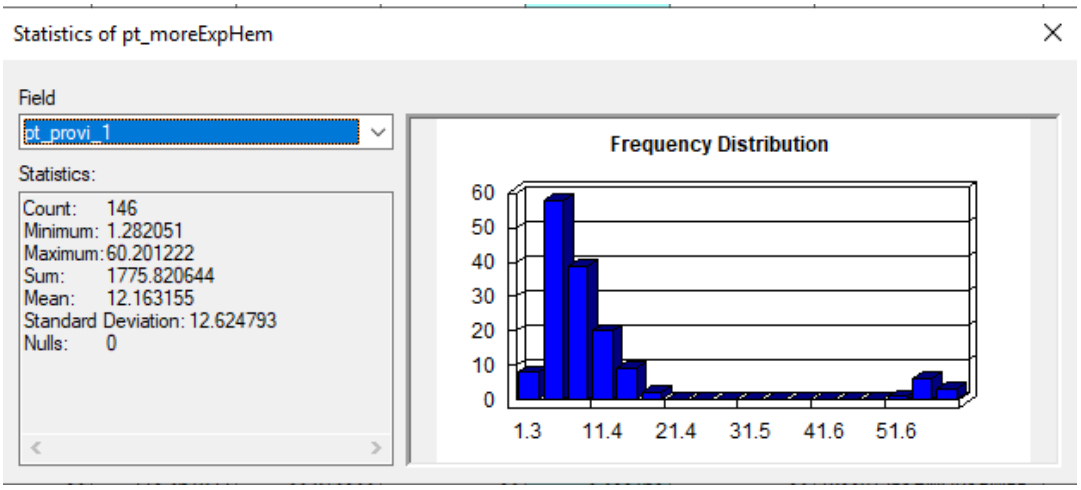
SUPPLMENTARY FIGURE 1: Sickle cell disease births in Georgia (2004-2016) by county of residence (n=2,019), with locations of specialty care.



Of the 2,006 newborns with SCD born in Georgia from 2004 through 2016 with available address information, 10% lived more than one hour drive from any specialty care option and another 14% lived within an hour of a specialty clinic with periodic access only.

SUPPLEMENTARY FIGURE 2: California's Sickle Cell Data Collection data from 2016-2018 highlights access to care





Median distance from a hematologist experienced in sickle cell disease care: 8.959763 miles.

California SCDC data between 2016-2018 shows that most patients covered by Medicaid in Los Angeles County (n=1,800) were located approximately 15-60 miles from hematologists experienced in SCD care.

SUPPLEMENTARY MATERIAL 2: Sickle Cell Data Collection (SCDC) surveillance data highlighting uptake of hydroxyurea for individuals with sickle cell disease (SCD) over time

- Hydroxyurea (HU) was approved by the Food and Drug Administration in 1998 for the treatment of severe SCD in adults and in 2017 for the treatment of pediatric patients. HU can decrease several complications of SCD, including severe acute pain episodes and acute chest syndrome, and may lead to fewer hospitalizations and improved survival.
- Although established as a valuable therapeutic agent, research suggests that HU is underutilized in actual clinical practice for patients with SCD.
- SCDC data from California and Georgia assessed rates of HU prescriptions filled for Medicaid recipients with SCD between 2006-2018. In 2006, the percentage of HU use was 26% in California and 24% in Georgia among Medicaid beneficiaries with SCD who had (1) at least one occurrence of acute chest syndrome or (2) three acute pain episodes. These percentages rose to 33% and 35% in 2011 and to 37% and 38% in 2018, respectively. HU use was assumed to have occurred if the beneficiary filled one or more prescriptions for HU during the year (Figure 4).
- While the HU utilization among Medicaid beneficiaries with SCD who lived in California or Georgia increased, it may be noted that many beneficiaries with severe complications of SCD still do not use HU, highlighting the need to address barriers to its use, including concerns about safety, adherence, and access to care.

SUPPLEMENTARY MATERIAL 3: Utility of Sickle Cell Data Collection data

Descriptions and analyses derived from surveillance data in California and Georgia are now available for clinicians, patients, policy makers and the public. Users can access maps and figures of aggregate data by year, including de-identified demographic information (patients by county of residents, age, and sex) and hospital utilization information (admissions, lengths of stays, 30-day re-admissions, emergency department utilization, payer information, etc.).