

## Hemoglobinopathies beyond childhood: Demographics characteristics of pregnant women – 2007-2008 Michigan Health Outside Pregnancy Survey (HOPS)

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**Background:** The prevalence of all hemoglobinopathies, including sickle cell disease (SCD), in the United States has yet to be determined. Since 1987, the Michigan NBS Program has screened for sickle cell disease allowing determination of the Michigan-specific newborn incidence. Little is known about the adult population born before 1987, and Michigan's current efforts are targeted to address this gap. There is not much information available for other hemoglobinopathies in Michigan (screening for thalassemias began in 2010).

**Study Question:** Are there any demographic differences in Hemoglobinopathy screening between women born before mandatory NBS and those born after?

**Methods:** Health Outside Pregnancy Survey (HOPS) is a structured mail survey developed by DGPHCDE at MDCH. The sampling frame was drawn from live birth records from 2007-08; low birthweight and race (African American) were used for oversampling. Survey data was weighted for estimating the prevalence of Hemoglobinopathies among women born before and after 1987 when NBS became mandatory for SCD from the answer to a particular question related to testing and diagnostic. Bivariate analyses and crude OR were used for comparing the two groups. Due to small number of those born after 1987, a proxy was needed: age categorization below and after 25 years of age.

**Results:** Of the 239,078 mothers represented by the data, an estimated 18,939 (8.0%, CI: 5.8-10.8) had ever been screened for and 6,269 (2.6%, CI: 1.4-4.9) had been diagnosed with a Hemoglobinopathy. The proportion of women screened who were born after NBS implementation (9.4%, CI: 6.0-14.6) was not significantly higher than for those born before (7.2%, CI: 4.7-10.0; crude OR: 1.4, CI: 0.7-2.7). Among all screened women, 78.0% (CI: 62.4-88.4) attended at least some college, compared to 22.0% (CI: 11.6-37.6) who received a high school diploma or less. Over 61% (CI: 45.1-75.2) delivered two or more children, while the remaining 38.8% (CI: 24.8-54.9) had only one. The proportion of women with private health insurance was 60.8% (CI: 43.2-76.0) and 39.2% (CI: 24.1-56.8) received Medicaid. Crude odds ratios showed no significant differences in demographics between the two groups: education COR = 1.1 (CI: 0.3-4.8), parity COR = 3.3 (CI: 0.8-13.2), and insurance COR = 1.5 (CI: 0.5-4.4).

**Conclusion:** The prevalence of Hemoglobinopathy screening and diagnosis in women born before and after 1987 (>25 and <25) is not significantly different.

**Public Health Implications:** Assessment of Hemoglobinopathy screening and diagnosis among those born before NBS implementation may help discover gaps in services.