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# GEORGIA PHRESH FINDINGS

Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies

#### November 2014

# Hydroxyurea Use and Measurement

People with sickle cell disease (SCD) in the United States are living longer, healthier lives because of advances in treatment and prevention of complications. One of the goals of the PHRESH project was to find out how well those advances are reaching individuals in Georgia. Another goal was to help the Centers for Disease Control and Prevention (CDC) develop practical ways to collect data on SCD-related objectives for Healthy People 2020 (HP2020).

Hydroxyurea drug therapy has been shown to reduce complications associated with SCD in adults and children, improve quality of life, and increase longevity. Increased use of this treatment fulfills HP2020 Blood Disorders and



Blood Safety objectives 5: "Increase the proportion of persons with hemoglobinopathies who receive disease modifying therapies." We used RuSH data to determine the proportion of individuals who met diagnostic and clinical criteria for hydroxyurea treatment and filled a prescription for the medication during the surveillance period of 2004-2008. This brief presents our findings and discusses options for ongoing tracking of this HP2020 objective.

#### Indications for Use

Hydroxyurea—developed as a cancer treatment—has been shown to reduce episodes of pain and acute chest syndrome, to reduce anemia and the need for transfusions, and to improve the quality of life in children and adults with HbSS and HbS $\beta^0$  thalassemia. There is evidence from around the world that individuals with these types of SCD who are taking hydroxyurea are living longer than those who are not. Currently, there is little data showing benefit to persons with HbSC or HbS $\beta^+$  thalassemia. Our surveillance data are unique in allowing us to assess hydroxyurea use in individuals who have the two specific types of SCD with evidence of benefit.

In addition to the specific types of SCD for which the drug is indicated, clinical guidelines in place during the five-year surveillance period recommended hydroxyurea treatment for patients experiencing the most acute complications – specifically, those who had one episode of acute chest syndrome or three episodes of SCD crisis within a year. In our surveillance dataset, we identified the individuals who met at least one of these clinical indications for hydroxyurea and, of those, the proportion who filled a prescription for it. We analyzed the data separately for children (0-19 years of age) and adults (20 years of age and older) because the evidence base for hydroxyurea use in children was less firmly established in 2004-2008 than it is today.



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#### Results

RuSH surveillance identified 16,504 individuals with confirmed, probable, or possible SCD who lived in Georgia between 2004 and 2008. We have public health insurance claims data matched to roughly three-fourths of these (12,340), which we used to determine who met the clinical criteria for hydroxyurea use described above. RuSH data include 4,288 cases for which the specific type of SCD is confirmed; and 2,840 of these have HbSS or HbS $\beta^0$  thalassemia. We have public health insurance claims data matched to approximately three-quarters of cases (2,131) in this group as well. Table 1 shows the proportion of individuals meeting treatment criteria in both groups that filled at least one prescription for hydroxyurea.

### Conclusion

Among all possible cases of SCD, 30% of individuals (29% of children, 32% of adults) who met the clinical criteria for hydroxyurea treatment filled a prescription. Among confirmed cases with the SCD types for which hydroxyurea has demonstrated benefit, the portion meeting clinical criteria who received hydroxyurea increased to 38% (36% of children, 42% of adults). These results indicate that hydroxyurea was underutilized in Georgia in 2004-2008.

Table 1. Hydroxyurea Treatment in Children and Adults Who Met Clinical Criteria, 2004-2008 <sup>1</sup>			
Population and age group <sup>2</sup>	Met clinical criteria <sup>3</sup>	Filled a prescription for hydroxyurea	
	Number	Number	Percent
Confirmed, probable, or possible SCD	2,862	858	30%
0-19 years of age	1,581	453	29%
20 years of age or older	1,281	405	32%
Confirmed HbSS or HbSβ <sup>0</sup> thalassemia	1,429	537	38%
0-19 years of age	952	339	36%
20 years of age or older	477	198	42%

<sup>1</sup>Data: Georgia RuSH cases matched to Medicaid, CHIP, or State Health Benefit Plan claims <sup>2</sup>Age as of the date when clinical criteria were met

<sup>3</sup>Clinical criteria: At least 1 acute chest syndrome or 3 SCD crises within the past 365 days

Currently, few data sources other than clinical center-based registries allow identification of individuals with specific types of SCD. However, claims-based health insurance datasets can be used to identify the population of all individuals with SCD who meet clinical criteria and the proportion for whom a hydroxyurea prescription is filled. Thus, claims data represent a feasible and satisfactory source for baseline and ongoing measurement of hydroxyurea use to track adherence to guidelines and achievement of HP2020 objectives.

A <u>2014 NIH Expert Panel Report</u> includes evidence-based guidelines that recommended increased adoption of hydroxyurea in the care of individuals with SCD. These guidelines and our booklet, <u>Sickle Cell Disease Treatment: Important Information</u> <u>for Patients and Health Care Providers</u>, further discuss the evidence, risks, and benefits of hydroxyurea.

Update: See the <u>11/19/2014 media advisory</u> from NIH on new, positive findings regarding hydroxyurea use with TCD to reduce stroke risk.

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