CDC's Sickle Cell Disease Surveillance History

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

The Centers for Disease Control and Prevention (CDC) and participating states began sickle cell disease (SCD) surveillance (monitoring) in 2010. SCD surveillance involves collecting information on diagnoses, treatment, and healthcare access for people with SCD in the United States. CDC and participating states developed many educational materials based on this information.

CDC coordinated these efforts as part of the three projects outlined below. All three used similar data sources, but each had a different funding source and amount. These differences influenced the number of participating states.

	Registry and Surveillance System for Hemoglobinopathies (RuSH)	Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies (PHRESH)	Sickle Cell Data Collection (SCDC) Program
Duration	2010—2012	2012—2014	Ongoing since 2015
Participating states	CA, FL, GA, MI, NY, NC, and PA	CA, GA, and MS	CA (since 2015) and GA (since 2016)
Funding source	Interagency agreement between National Institutes of Health, National Heart, Lung, and Blood Institute, and CDC's Division of Blood Disorders	Various CDC funding sources	CDC (Association of University Centers on Disabilities) and CDC Foundation (Pfizer, Bioverativ, Global Blood Therapeutics)
Funding amount	2 year project totals: $1,100,000 per state	2 year project totals: MS: $250,000 GA: $420,000 CA: $748,000	Annual totals: CA: $400,000 GA: $123,600
Purpose	To identify and collect data on people living with SCD or thalassemia in the participating states	CA and GA: To evaluate and validate data collected during RuSH and to share findings from the project MS: To identify and collect data on people living with SCD in the state	To study trends in diagnosis,treatment, and healthcare access and to share findings with audiences who will drive policy and healthcare changes that improve the lives of people with SCD
Years of data	2004—2008	2004—2008	2004—2016 (data after 2016 will be collected as it becomes available)
Data sources	• Newborn screening • Vital records (birth and • death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims	• Newborn screening • Vital records (birth and • death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims	• Newborn screening • Vital records (birth and • death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims
Accomplishments	• State Data Fact sheets • Medscape Commentary • Strategies from the Field: Health Promotion • Strategies from the Field: Data Collection • Peer-reviewed publications*	• Data Validation Report (available upon request) • Thalassemia fact sheet • Survey of Provider Information Needs • Sickle Cell Disease Treatment: Important Information for Patients and Health Care Providers • Hydroxyurea Use and Measurement • Peer-reviewed publications*	• Fact sheets • Infographics • Webinars • Data report • Research Plan • CDC Public Health Grand Rounds Session • Peer-reviewed publications*

* See list of peer-reviewed articles on back.

For more information about SCD, visit: www.cdc.gov/ncbddd/sicklecell
For more information about thalassemia, visit: www.cdc.gov/ncbddd/thalassemia

SCDC
Sickle Cell Data Collection

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Published peer-reviewed articles

RuSH

- Wang Y, Kennedy J, Caggana M, Zimmerman R, Thomas S, Berninger J, Harris K, Green NS, Oyeku S, Hulihan M, Grant AM, Grosse SD. Sickle cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity. Genet Med. 2013 Mar;15(3):222–8.

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- Wang Y, Liu G, Caggana M, Kennedy J, Zimmerman R, Oyeku SO, Werner EM, Grant AM, Green NS, Grosse SD. Mortality of New York children with sickle cell disease identified through newborn screening. Genet Med. 2015 Jun;17(6):452–9.

PHRESH

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cdc.gov/ncbddd/sicklecell

cdc.gov/ncbddd/thalassemia