

# 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.

	<b>Registry and Surveillance System for Hemoglobinopathies (RuSH)</b>	<b>Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies (PHRESH)</b>	<b>Sickle Cell Data Collection (SCDC) Program</b>
<b>Duration</b>	2010—2012	2012—2014	Ongoing since 2015
<b>Participating states</b>	CA, FL, GA, MI, NY, NC, and PA	CA, GA, and MS	CA (since 2015) and GA (since 2016)
<b>Funding source</b>	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, Bioerativ, Global Blood Therapeutics)
<b>Funding amount</b>	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
<b>Purpose</b>	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
<b>Years of data</b>	2004—2008	2004—2008	2004—2016 (data after 2016 will be collected as it becomes available)
<b>Data sources</b>	<ul style="list-style-type: none"> <li>Newborn screening</li> <li>Vital records (birth and death records)</li> <li>Hospital discharge</li> <li>Emergency room</li> <li>Clinical records</li> <li>State Medicaid claims</li> </ul>	<ul style="list-style-type: none"> <li>Newborn screening</li> <li>Vital records (birth and death records)</li> <li>Hospital discharge</li> <li>Emergency room</li> <li>Clinical records</li> <li>State Medicaid claims</li> </ul>	<ul style="list-style-type: none"> <li>Newborn screening</li> <li>Vital records (birth and death records)</li> <li>Hospital discharge</li> <li>Emergency room</li> <li>Clinical records</li> <li>State Medicaid claims</li> </ul>
<b>Accomplishments</b>	<ul style="list-style-type: none"> <li><a href="#">State Data Fact sheets</a></li> <li><a href="#">Medscape Commentary</a></li> <li>Strategies from the Field: <a href="#">Health Promotion</a></li> <li>Strategies from the Field: <a href="#">Data Collection</a></li> <li>Peer-reviewed publications*</li> </ul>	<ul style="list-style-type: none"> <li>Data Validation Report (available upon request)</li> <li><a href="#">Thalassemia fact sheet</a></li> <li><a href="#">Survey of Provider Information Needs</a></li> <li><a href="#">Sickle Cell Disease Treatment: Important Information for Patients and Health Care Providers</a></li> <li><a href="#">Hydroxyurea Use and Measurement</a></li> <li>Peer-reviewed publications*</li> </ul>	<ul style="list-style-type: none"> <li><a href="#">Fact sheets</a></li> <li><a href="#">Infographics</a></li> <li><a href="#">Webinars</a></li> <li><a href="#">Data report</a></li> <li><a href="#">Research Plan</a></li> <li><a href="#">CDC Public Health Grand Rounds Session</a></li> <li>Peer-reviewed publications*</li> </ul>

\* See list of peer-reviewed articles on back.

For more information about SCD, visit: [www.cdc.gov/ncbddd/sicklecell](http://www.cdc.gov/ncbddd/sicklecell)  
For more information about thalassemia, visit: [www.cdc.gov/ncbddd/thalassemia](http://www.cdc.gov/ncbddd/thalassemia)



# 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. Sick cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity. *Genet Med*. 2013 Mar;15(3):222–8.
- Paulukonis ST, Harris WT, Coates TD, Neumayr L, Treadwell M, Vichinsky E, Feuchtbaum LB. Population based surveillance in sickle cell disease: methods, findings and implications from the California registry and surveillance system in hemoglobinopathies project (RuSH). *Pediatr Blood Cancer*. 2014 Dec;61(12):2271–6.
- Hulihan MM, Feuchtbaum L, Jordan L, Kirby RS, Snyder A, Young W, Greene Y, Telfair J, Wang Y, Cramer W, Werner EM, Kenney K, Creary M, Grant AM. State-based surveillance for selected hemoglobinopathies. *Genet Med*. 2015 Feb;17(2):125–30.
- 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

- Neunert CE, Gibson RW, Lane PA, Verma-Bhatnagar P, Barry V, Zhou M, Snyder A. Determining Adherence to Quality Indicators in Sick Cell Anemia Using Multiple Data Sources. *Am J Prev Med*. 2016 Jul;51(1 Suppl 1):S24–30.

## SCDC

- Hulihan M, Hassell KL, Raphael JL, Smith-Whitley K, Thorpe P. CDC Grand Rounds: Improving the Lives of Persons with Sick Cell Disease. *MMWR Morb Mortal Wkly Rep*. 2017;66:1269–1271.
- Paulukonis ST, Eckman JR, Snyder AB, Hagar W, Feuchtbaum LB, Zhou M, Grant AM, Hulihan MM. Defining Sick Cell Disease Mortality Using a Population-Based Surveillance System, 2004 through 2008. *Public Health Rep*. 2016 Mar-Apr;131(2):367–75.
- Paulukonis ST, Feuchtbaum LB, Coates TD, Neumayr LD, Treadwell MJ, Vichinsky EP, Hulihan MM. Emergency department utilization by Californians with sickle cell disease, 2005–2014. *Pediatr Blood Cancer*. 2017 Jun;64(6).
- Snyder AB, Lane PA, Zhou M, Paulukonis ST, Hulihan MM. The accuracy of hospital ICD-9-CM codes for determining sickle cell disease genotype. *J Rare Dis Res Treat*. 2017;2(4):39–45.

[cdc.gov/ncbddd/sicklecell](https://www.cdc.gov/ncbddd/sicklecell)

[cdc.gov/ncbddd/thalassemia](https://www.cdc.gov/ncbddd/thalassemia)