



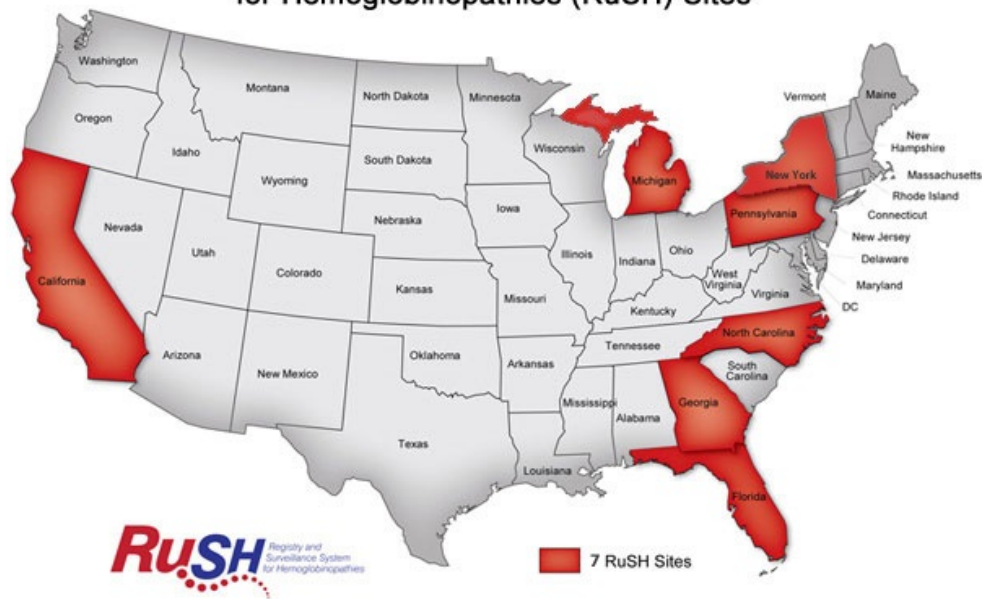
Why the RuSH Project?

The Centers for Disease Control and Prevention (CDC) is working with the National Heart, Lung, and Blood Institute (NHLBI) to plan and implement a pilot data collection system for hemoglobinopathies, which is called RuSH-Registry and Surveillance System for Hemoglobinopathies. Currently, there is no way to determine the number of people who have sickle cell disease, thalassemia and other hemoglobinopathies (disorders affecting red blood cells), nor to fully describe how these conditions affect people's health.

New York State is one of seven states with funding to participate in the RuSH project. The goal of this project is to establish a population-based surveillance system for hemoglobinopathies in New York. By working with the Newborn Screening Program, Hemoglobin Specialty Care Centers, the Medicaid program, the Congenital Malformations Registry, and other existing state computer systems, the New York RuSH team will be able to collect information on children and adults in New York State who have hemoglobinopathies. The project will help us to determine the number of people with these diseases, which will allow us to assist public health professionals in planning for education, community outreach and resource allocation.

States Participating in RuSH Project

Registry and Surveillance System for Hemoglobinopathies (RuSH) Sites



What are the goals of NY - RuSH?

- Determine the number of newly-diagnosed people and those living with hemoglobinopathies (sickle cell disease and thalassemia) in New York State.
- Describe where people with hemoglobinopathies live in New York State and their characteristics (such as age, race/ethnic background).
- Describe the cause of death and the number of people in New York State who had hemoglobinopathies and died.
- Describe how people get health care, its costs, and where different types of services are located for people affected by hemoglobinopathies in New York State.

Who Benefits from RuSH?

By standardizing the types of public health information collected in states like New York, the RuSH project will lead to a better understanding of the health status of people living with sickle cell disease and thalassemia. It will also help us determine how many people have sickle cell disease or thalassemia. This project will raise public awareness about these diseases. In addition, it could lead to better research, increased funding and improve public health programs related to sickle cell disease and thalassemia. In countless ways, everyone benefits!

Find out more information, contact resources near you, and together, we can make a difference!

CDC Hemoglobinopathies Monitoring (RuSH)

www.cdc.gov/ncbddd/hemoglobinopathies/ - Phone: (800) 232-4636

National Organization for Rare Disorders (NORD)

www.rarediseases.org - Phone: (203) 744-0100

Sickle Cell Disease Association of America, Inc.

www.sicklecelldisease.org - Phone: (410) 528-1555

Sickle Cell Thalassemia Patients Network

www.sctpn.net - Phone: (877) 812-4216

Cooley's Anemia Foundation

www.thalassemia.org - Phone: (800) 522-7222

Queens Sickle Cell Advocacy Network

www.qscan.org - Phone: (718) 712-0873

Parent to Parent of New York State

www.parenttoparentnys.org - Phone: (866) 727-6970

NY- RuSH Project Partners:

New York State Department of Health
Newborn Screening Program, Wadsworth Center
Congenital Malformations Registry, Center for Environmental Health
Division of Family Health, Center for Community Health
Medicaid Program, Office of Health Insurance Programs

New York City Department of Health and Mental Hygiene
Office of Vital Statistics

NY- RuSH Advisory Committee:

- **Rita Bellevue**, MD, New York Methodist Hospital
- **Donnette Carroll**, President, Sickle Cell Thalassemia Patients Network
- **Gina Cioffi**, Esq., Cooley's Anemia Foundation
- **Patricia Giardina**, MD, New York Presbyterian Hospital
- **Nancy Green**, MD, Columbia University Medical Center
- **Katharine Harris**, MBA, Newborn Screening Program, New York State Department of Health
- **Suzette Oyeku**, MD, MPH, Albert Einstein College of Medicine, The Children's Hospital at Montefiore
- **Patricia Shi**, MD, Mount Sinai Hospital
- **Beth Shaz**, MD, New York Blood Center
- **Richard Sills**, MD, SUNY Upstate Medical Center
- **Kusum Viswanathan**, MD, Brookdale University Hospital and Medical Center,
- **Barbara Wallace**, MD, MSPH, Division of Chronic Disease and Injury Prevention, New York State Department of Health

For additional information, please contact:

The NY-RuSH Project

NYS Department of Health

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