Sickle Cell Disease

Sickle cell disease is one of a group of inherited red blood cell disorders called hemoglobinopathies. In sickle cell disease, the red blood cells become hard and sticky and look like a C-shaped farm tool called a “sickle.” The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems such as infection, acute chest syndrome and stroke. It is estimated that sickle cell disease affects 90,000 to 100,000 Americans.

2012 Accomplishments

- Developed the Registry and Surveillance for Hemoglobinopathies (RuSH) “Strategies from the Field: Data Collection” and “Strategies from the Field: Health Promotion.” The publications, which are available on CDC’s website, showcase the various methods that can be adapted by states to develop state-specific population-based data collection and community engagement to improve the lives of people with sickle cell disease and thalassemia.

- Implemented Public Health Research Epidemiology and Surveillance for Hemoglobinopathies (PHRESH), a demonstration project that focuses on three areas: surveillance, health promotion and prevention awareness, and laboratory capacity building. The project is intended to expand upon, and learn more about, the data collected from RuSH and is being piloted in California, Mississippi, and Georgia.

- Developed and submitted a manuscript entitled, “Invasive Pneumococcal Disease among Children with and without Sickle Cell Disease in the United States, 1998-2009” to the Pediatric Infectious Disease Journal. The manuscript describes an assessment of trends in invasive pneumococcal disease in children less than 18 years of age with sickle cell disease.

AJ’s Story

At 19 years old, AJ is an accomplished singer and sickle cell disease advocate, and doesn’t let his condition keep him from reaching his goals.

To read AJ’s story, visit: www.cdc.gov/ncbddd/SickleCell/stories.htm
2012 Accomplishments (continued)

- Hosted a monthly Public Health Webinar Series on Hemoglobinopathies. The purpose of this webinar series is to offer a hemoglobinopathies learning collaborative platform for providers, general public, educators, and scientists.

- Partnered with the Sickle Cell Disease Association of America and the National Baptist Congress of Christian Education to develop and disseminate a new video entitled, “Sickle Cell Disease Education and Awareness in Your Community.” The video raises awareness and promotes education of sickle cell disease by illustrating the public health role, community involvement, and individual level impact of sickle cell disease in the United States.

- Hosted the 2nd National Conference on Blood Disorders in Public Health. The purpose of this conference was to promote the health and improve outcomes among people with blood disorders.

Looking to the Future

There is still much to learn about sickle cell disease and how to prevent and manage complications associated with the disease. The impact of genetic, environmental, behavioral, and other risk factors on sickle cell disease is not fully understood. An estimated 90% of people with sickle cell disease are unable to attain the resources they need to improve or maintain their health and proven therapies are not being used. It is estimated that 30% or less of eligible people with sickle cell disease are treated with hydroxyurea, which is known to reduce pain crises, stroke, pulmonary complications and disability.

Strengthening CDC’s sickle cell disease programs and activities in the areas of surveillance, health promotion, technical assistance to community-based organizations and state health departments can fill the public health needs essential for saving, lengthening, and improving the quality of lives of people with sickle cell disease.

Collaborating with our many public health partners – other federal and state agencies, academia, and professional and community-based organizations – The National Center on Birth Defects and Developmental Disabilities’ Division of Blood Disorders improves the lives of people at risk or affected by sickle cell disease.
Notable Scientific Publications


To view the annual report online, visit: www.cdc.gov/ncbddd/2012AnnualReport

For more information about sickle cell disease, visit: www.cdc.gov/SickleCell