Sickle Cell Disease and Public Health

Mary Hulihan

Centers for Disease Control and Prevention
National Center for Birth Defects and Developmental Disabilities
Division of Blood Disorders

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What is Sickle Cell Disease?

- Normal red blood cells
- Abnormal, sickled, red blood cells (sickle cells)
- RBCs flow freely within blood vessel
- Sticky sickle cells

[Images of normal and sickled red blood cells]

[Image of skin lesion and abnormal blood flow]

legacy.owensboro.kctcs.edu
www.sickleanaemias.com
www.atlasdermatologico.com
http://www.medindia.net
Who has Sickle Cell Disease?

Among newborn American infants, SCD occurs in approximately:
- 1 in 400 blacks
- 1 in 1,400 to 1 in 36,000 Hispanics
- 1 in 80,000 whites
- 1,800-2,000 births/year

- 200,000-230,000 newborns in Africa every year\(^1\)
- 1 in 150 Jamaican births\(^2\)
- 5,200 newborns in India every year\(^3\)
- Prevalence of 0 – 5.27% in Saudi Arabia\(^4\)

\(^1\)WHO, 1994
\(^2\)King, 2007
\(^3\)Verma, 2002
\(^4\)el-Hazmi, 1996
Health Burden

- 80,000 to 100,000 Americans living with SCD
- People with the most severe form of SCD have 2-3 decades shorter life expectancy than other Americans
- Emergency department visits associated with SCD average 200,000 per year, or roughly 2 per person per year
- About 20-30% of children with the most severe form of SCD experience stroke, and cognitive impairment is common
- Due to frequent pain crises, children with SCD miss an average of 18 days of school each year

Economic Impact

- The annual cost is estimated to be ~$2 billion.
- The total hospital costs for hospitalizations principally for SCD are approximately $488 million.
- Total direct healthcare annual costs vary from $10,700 for children ages 0-9 to $34,300 at ages 30-39.
- Mean medical expenditures for children with SCD are $11,000 for those enrolled in Medicaid and $14,800 for those with private insurance.
- Among hospital stays principally for SCD, 66% are paid for by Medicaid and 13% by Medicare.
- For children with SCD, 56% have public insurance, 33% private insurance, 4% another type of insurance, 7% are uninsured.

Kauf, 2009
Steiner, 2006
Amenda, 2010
Boulet, 2010
What is Public Health?

- The art and science dealing with the protection and improvement of community health by organized community effort and including preventive medicine and sanitary and social science.
- It helps us understand who the patients are; where they receive care; what are the barriers for prescribing and taking the drug; and what are the best methods for developing and disseminating materials to educate providers, patients, and families.
- The continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice. Such surveillance can monitor and clarify the epidemiology of health problems, to allow priorities to be set and to inform public health policy and strategies.

Mirriam Webster Dictionary
Why are Public Health Projects Needed?

- **GOAL:** Reduce SCD-related health complications
- Hydroxyurea has been reported to reduce pain crises, strokes, and death in severely affected children and adults
- Associated with a 40% reduction in mortality for adult SCD patients with similar beneficial effects in children and adolescents
- Saves more than $4000/year/Medicaid-enrolled patient compliant with the therapy
- 40% of eligible SCD patients are prescribed hydroxyurea
- 70% of eligible SCD patients who are prescribed the drug are not taking it as indicated

Lanzkron, 2006  Moore, 2000  Strouse, 2008  Wang, abstract
What is CDC doing?

- **Data collection and monitoring systems**
  - Registry and Surveillance for Hemoglobinopathies (RuSH) Project
    - 7 states (CA, MI, NC, GA, NY, FL, and PA) collect data on all people with SCD
    - February 2010- September 2012

- **Use data to identify opportunities for health promotion and prevention**
  - Monitor trends in key health indicators for population (i.e. HP2020)

- **Develop tools and resources for patients, providers, and families**
  - Sickle Cell Disease National Resource Directory
  - Toolkit for Living Well with Sickle Cell Disease

- **Foster collaboration among state and local partners including health departments (HDs), clinical centers, and community-based organizations (CBOs)**
  - Learning collaboratives and webinars
  - CDC lead multidisciplinary workgroups (Community Partnerships, Surveillance Design, Data Harmonization)
Surveillance Data Example

Sickle cell disease incidence rate by maternal country of birth for foreign-born non-Hispanic Black mothers (New York State birth: 2000-2008)
What still needs to be done?

- Evaluation and validation of surveillance methods
- Health Research, Education, and Promotion activities regarding HP2020 Blood Disorders topic areas
- Expansion of state data collection
- Dissemination of information
Thank You!

ibx5@cdc.gov
404-498-6724

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: www.cdc.gov

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