Public Health Implications of Sickle Cell Disease

The findings and conclusions in this presentation are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention

Melissa S. Creary, MPH
Division of Blood Disorders
National Center on Birth Defects and Developmental Disabilities

American Public Health Association
135th Annual Meeting
November 5, 2007

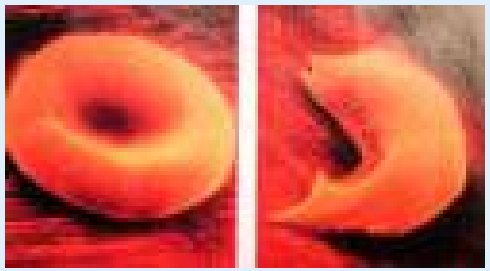
SAFER • HEALTHIER • PEOPLE

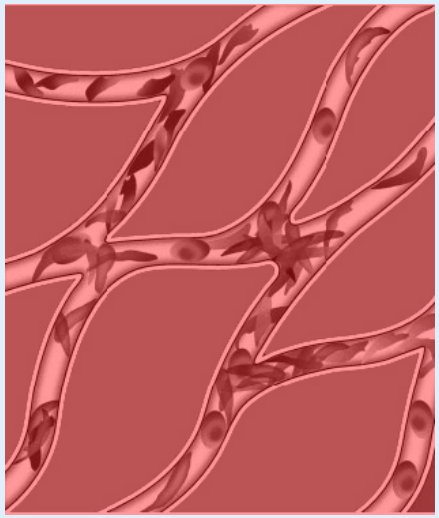
CDC™

What is Sickle Cell Disease (SCD)?

National Heart, Lung, and Blood Institute (NIH)

- A genetic blood disorder caused by abnormal hemoglobin that damages and deforms red blood cells
- In a state of low oxygen, sickle hemoglobin deforms red blood cells causing blockage in the small vessels.





What Do We Know?

Who It Affects *(NHLBI, 2007)*

- In the United States, SCD affects approx. 72,000 people.
- 1 out of 12 Blacks have sickle cell trait
  - Over 2 million Americans have sickle cell trait

What Happens

- Anemia, pain, infection, stroke, delayed puberty and growth

Treatment

- Medication, blood transfusions, bone marrow transplant, anti-sickling agents

Sickle Cell Trait

- Associated with lower odds of early preterm delivery and increased odds of multiple gestations *(Obstetrics & Gynecology, 2007)*
- Austin et al. found that sickle-cell trait is a risk factor for venous thromboembolism and that the proportion of venous thromboembolism among African Americans attributes to the mutation about 7% (*Blood, 2007)*
- There is a 25% risk when both parents are carriers. Genetic counseling, education, and family planning assistance are extremely important

Global Perspective

Renaissance of Sickle Cell Disease Research in the Genomic Era (Imperial College Press), 2006

- There are three epicenters of the sickle mutation in Africa:
  - Epicenter 1—Approx. 91,000 babies born each year
  - Epicenter 2—An estimated 26,000 born annually
  - Epicenter 3—Heterozygote frequency of 30%
- India (central states)—20%-25% sickle mutation
- Cuba (varied regions)—Heterozygote range from 3%-7%

Public Health Implications

- Current Prevalence
- Emerging Hispanic population with SCT in US
- Health Education and Promotion
  - Community, Provider, Patient, School

Public Health Implications

- Rural Outcomes
  - How are rural patients being cared for? What do they rely on for self management?
- Newborn Screening
  - What happens in terms of follow-up and counseling for the person with SCD or SCT *and* family?
- Transition Issues
  - What are the curriculum needs for parents and adolescents with SCD as they transition into adulthood? Who advocates for your care?

Patient Burden

- Pain
- Lack of Awareness
- Transition Issues
- Education
- Employment
- Insurance
- Psycho-social Concerns

Health Burden of SCD

National Heart, Lung, and Blood Institute, NIH - 1994

- Total health care costs for anemia $2.9 billion
- Sickle cell and related hemoglobinopathies accounted for 25% hospitalizations for anemias
- National Hospital Discharge Survey estimated 75,000 hospitalization/year for SCD, Average cost $63,000/hospitalization

Health Burden of SCD

Healthcare Cost and Utilization Project (HCUP), ARHQ – 2004

- The number of hospitalizations among adults with sickle cell disease (SCD) in 2004 was 83,149
- The total hospital costs for hospitalizations principally for SCD were approximately $488 million
- Among those hospital stays principally for SCD, 66 percent were paid by Medicaid and 13 percent were paid by Medicare

Scope of problem

- There is a need for a collaborative effort between federal agencies to pool resources to coordinate services across USA
  - Comprehensive care not available nationwide
  - 10 and 8 NIH and 4 HRSA funded sickle cell centers serve small percentage of the population
  - Current research advances not fully translated to patients outside of these centers

- Not enough funding for research, advocacy, and education compared to other common genetic disorders

Sickle cell disease: A question of Equity and Quality.

Smith LA et al. Pediatrics 2006;117;1763

Variable	SCD	Cystic Fibrosis
US prevalence	80,000	30,000
Federal Support (in millions $)	90	128
CF foundation revenue 2003		152,231,000
SCDAA revenue 2003	498,577	
Total NIH/private support (millions $)	90.4	280.2
Total support /per person affected with disease $	1130	9340

Past and Current Activities

- SCD: Current activities, public health implications, and future directions. (*Journal of Women's Health, 2007)*

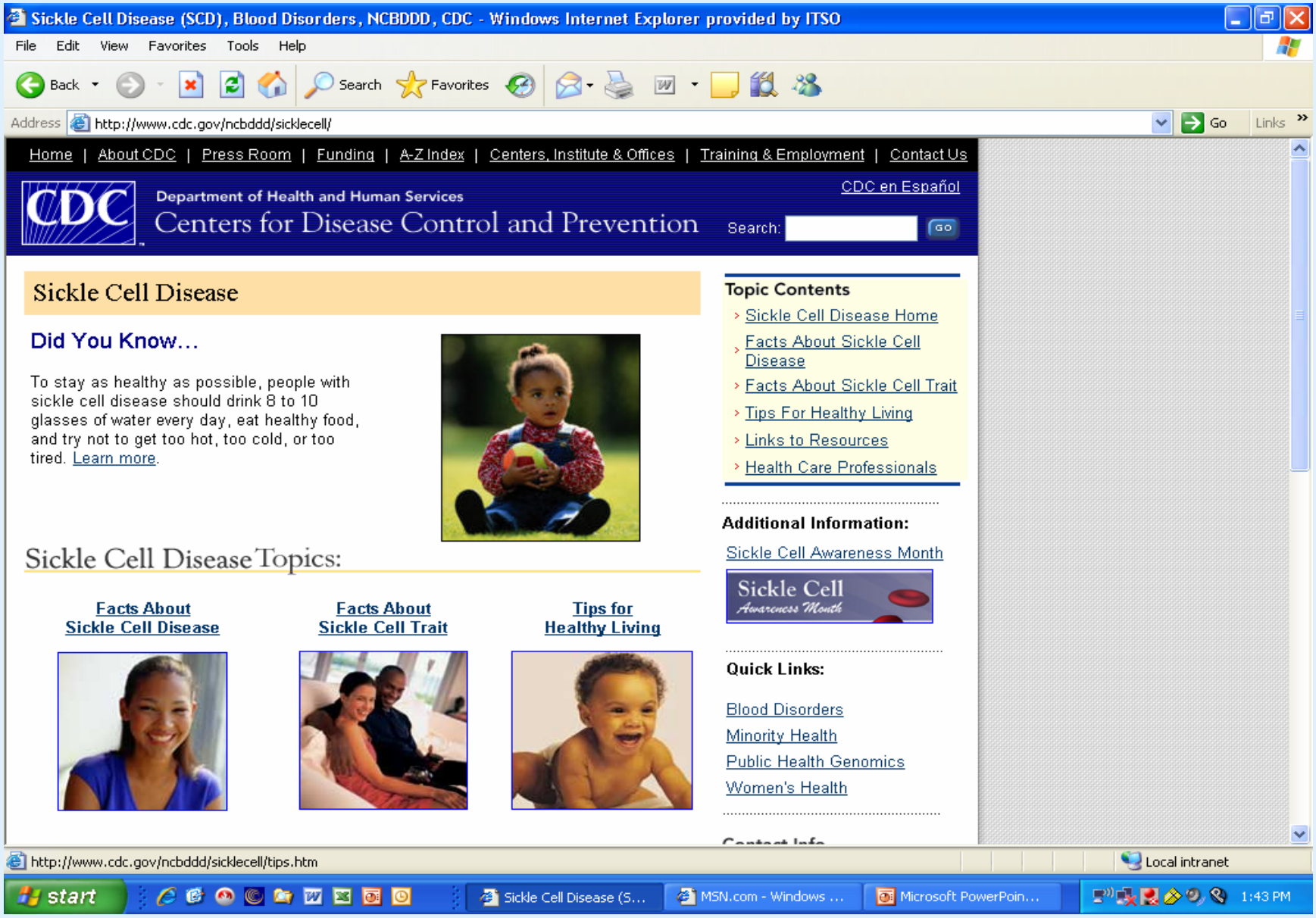
- National Center on Birth Defects and Developmental Disabilities
  - Newborn Screening Follow-up Studies
  - Mortality and Morbidity Studies
  - Genomic Studies
  - SCT
  - Collaborative Activities

Past and Current Activities

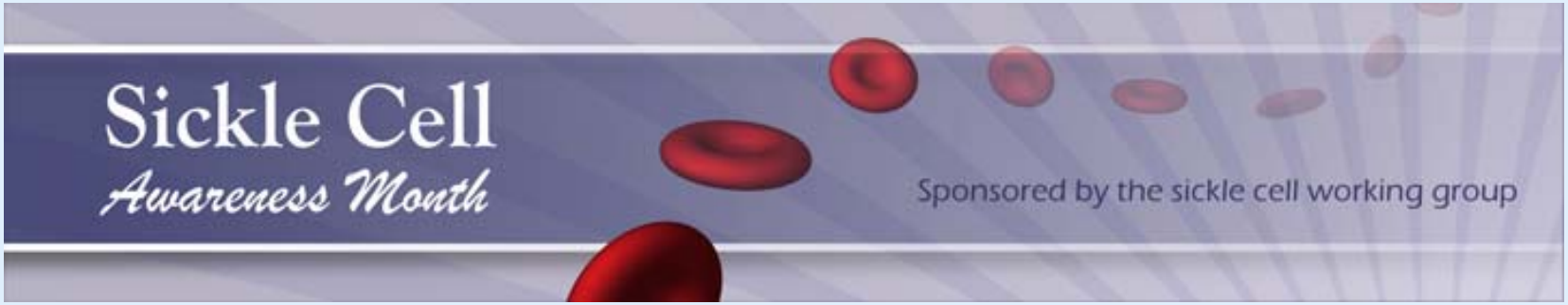
- National Center for Environmental Health
  - Quality Assurance and Proficiency Testing for Newborn Screening
- National Center for Zoonotic, Vector-Borne, and Enteric Diseases
  - SCD and Malaria
- National Center for Chronic Disease Prevention and Health Promotion
  - Women and SCD

CDC SCD Workgroup

- Convened initially January 2007
- Organized into 3 subgroups:
  - Epidemiology/Surveillance/Heath Research Services
  - Behavioral Sciences and Health Education (BSHE)
  - Laboratory/Genomics
- Agency-wide involvement



SAFER • HEALTHIER • PEOPLE™



- Internal Communication
  - CDC Connects
  - SCD Podcast

- External Communication
  - MMWR Notice to Readers
  - CDC.gov web feature

- Sickle Cell Screening by SC Foundation of GA will be available in tandem with the Red Cross blood drive at CDC.

What's Next?

- MCH Epi Conference Special Session
- 2nd Sickle Cell Symposium on Education and Research
- Intramural Projects
  - Population based study on maternal outcomes of women with SCD
  - Whole genome studies for SCT
  - Evaluation of barriers to Hydroxyurea use
- Continued federal and state collaboration

Contact Information

Melissa Creary
1600 Clifton Road, MS E64
Atlanta, GA 30333
Tel: 404-718-8607
mcreary@cdc.gov