

# Newborn Screening and Sickle Cell Trait

- Newborn screening (NBS) programs designed to identify infants with sickle cell disease
- “Byproduct” identification of infants with sickle cell trait
  - Benign state for the infant
  - May be an indicator of a couple at risk for subsequent pregnancies affected by sickle cell disease

# Identification of Possible Shifting Communities at Risk for Sickle Cell Trait

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# Confirmed Sickle Cell Trait

	1985	1995	2000	2005	Total
African American	75(68.2%)	109(58.9%)	127(48.5%)	154(49.4%)	465(53.5%)
<b>Hispanic</b>	<b>10(9.1%)</b>	<b>26(14.1%)</b>	<b>73(27.9%)</b>	<b>91(29.2%)</b>	<b>200(23.0%)</b>
White	14(12.7%)	33(17.8%)	57(21.8%)	50(16.0%)	154(17.7%)
Asian	1 (0.9%)	4(2.2%)	0	1(0.3%)	6(0.7%)
Other	4(3.6%)	6(3.2%)	5(1.9%)	8(2.6%)	23(2.7%)
Unknown	6(5.4%)	7(3.8%)	0	8(2.6%)	21 (2.4%)

# Colorado Latino Population

- Growth in the Latino population in Colorado: the changing birth cohorts
  - 1995 - 11,522 babies born to Latino mothers (makes up 21% of all births)\*
  - 2000 - 18,231 (a 37% increase from 1995) (makes up 28% of all births)\*
  - 2004 - 21,738 (a 16% increase from 2000) (makes up 32% of all births)\*
- This increasing trend of births to Latina mothers is significant ( $p < 0.01$ )

\*Information gathered from the Colorado Health Information dataset

# Big Picture

- Sickle cell trait and disease occurs in more than one ethnic group
  - Outreach to at-risk populations must be tailored to specific cultural expectations and needs
  - Awareness should be increased in unsuspecting at-risk populations

# Implementation of Genetic Counseling Services Through Community Public Health Clinics: Sickle Cell Trait Pilot Project

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# Background

- In Colorado, providers notified of infant's sickle cell trait status
  - Family may not receive results or appropriate genetic counseling
  - Appropriate laboratory testing may not be available
- Risk in future pregnancies can only be estimated with appropriate lab testing
  - CBC, hemoglobin separation

# Project Goals - 1

- Create sickle cell trait outreach programs
  - Utilize existent community/public health clinics
  - Offer consumer education and genetic counseling for at-risk individuals
  - Provide free laboratory testing (CBC, hemoglobin separation) for interested individuals

# Project Goals - 2

- Sustainability
  - Professional education for public and community health providers regarding sickle cell disease, sickle cell trait and recognition of at-risk individuals
  - Sustain genetic counseling services by training community members

# Results - 1

- Identification of appropriate community health clinics in Denver, Fort Collins and Colorado Springs

Site	Initial Contact	Clinic Held	
Denver Health System	Yes	Yes	Nov 2006
Larimer County PH Clinic	Yes	No	*
Weld County PH Clinic	Yes	No	*
Colorado Springs Pediatric Multi-specialty Clinic	Yes	Yes	Oct 2006

\*Clinics in Larimer and Weld Counties canceled due to lack of interest

## Results - 2

- Sickle cell trait counseling training for two lay community members
  - Completed May, 2006 in New Britain, Connecticut
  - One each from Denver and Colorado Springs

## Results - 3

- Advertisement to families of infants identified with sickle cell trait
  - Fliers included in letters to providers
  - Direct phone contact with families for preceding 6 months
- Follow-up fliers and phone contact
  - Fliers included in letters sent August, September
  - Phone confirmation of plans to attend

# Results - 4

- 158 eligible families were contacted
- 54 families expressed interest
- 9 family units attended clinics
  - 3 family units were Spanish speaking only
  - Majority were of non-African descent
- Total of 21 tested
  - Results:
    - 8 AS identified, 1 co-existent  $\alpha$  thal
    - 13 normal

## Results - 5

- Follow-up phone calls November, 2006
  - Discussion of laboratory testing
  - Assessment of family satisfaction completed

# Results - 6

- Satisfaction Survey
  - All families agreed services were helpful
  - All thought the service should be continued
  - All families thought they now have a better understanding of Sickle Cell Trait
  - 2 families suggested a future clinic should be held in NW Denver
  - 1 commented it was a little “Big-Brotherish”

# Big Picture

- Sickle cell trait and disease occurs in more than one ethnic group
  - Outreach services need to consider the cultural expectations and needs (including language)
- Serves as a test-case
  - Introduction of awareness, educations and genetics counseling services into potentially unsuspecting at-risk populations