

# CDC's Sudden Unexpected Infant Death Case Registry Pilot Program

Lena Camperlengo, RN, MPH, DrPH(c)  
EGS, Inc.

March 8, 2010

AMCHP 2010 Annual Conference  
National Harbor MD

SAFER • HEALTHIER • PEOPLE™



# Overview

- Definitions
- Background
- SUID-CR Objectives
  - Individual Based Variables
  - Systems Based Variables
  - Categorization
- SUID-CR Pilot Program

# Definitions

# SUID definition

- SUID = sudden, unexpected infant death
- Group of infant deaths that occur suddenly and unexpectedly, and whose manner and cause of death are not immediately obvious prior to investigation

# Sudden Infant Death Syndrome (SIDS)

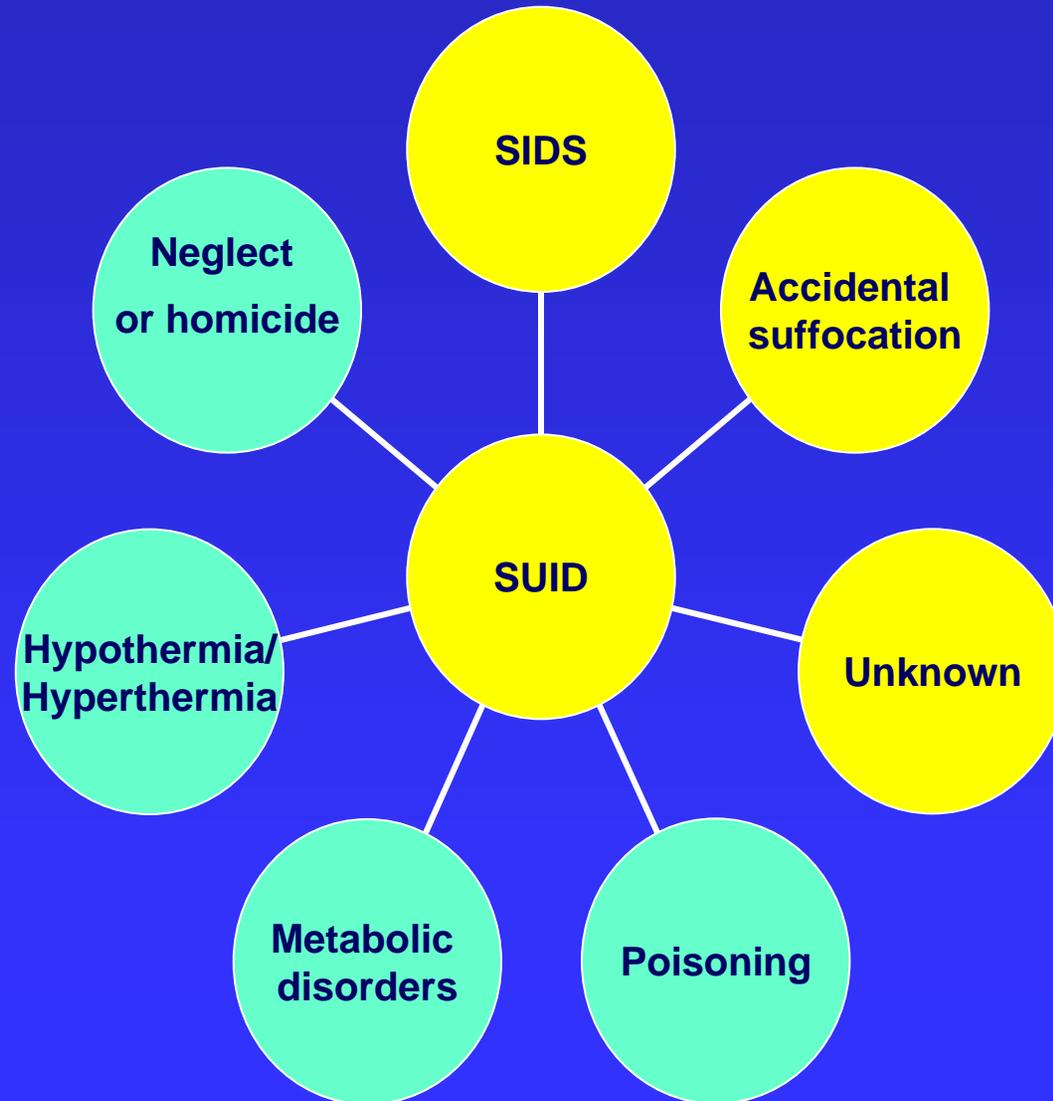
- Most common SUID
- ICD-10 Code: R95
- “Sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete ***autopsy, examination of the death scene, and review of the clinical history.***”

\* Willinger M, James LS, Catz C. Pediatric Pathology 1991

# Other Common SUID

- ASSB
  - Accidental Suffocation and Strangulation in Bed
  - ICD-10 code W75
- Unknown Cause
  - Difficult to distinguish from SIDS
  - ICD-10 code R99

# Some causes of infant deaths that occur suddenly and unexpectedly without an obvious cause



# SUID Explained vs. Unexplained

## Explained

- Poisoning
- Head injury
- Metabolic disorder
- Neglect or homicide
- Hypo or hyperthermia
- Accidental suffocation?

## Unexplained

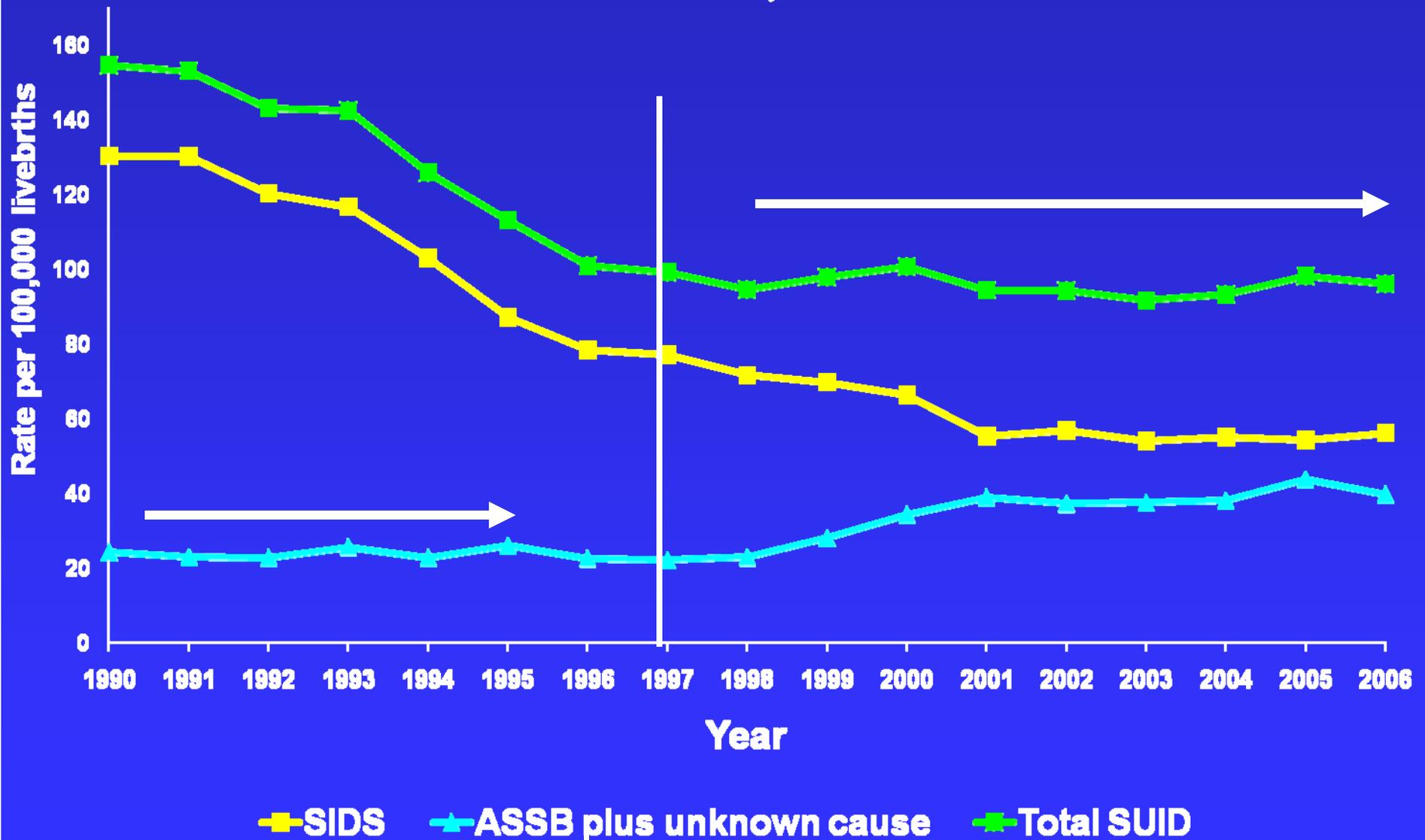
- SIDS
- Cause unknown or unspecified
- SIDS, but cannot rule out suffocation from unsafe sleep environment

# Background

# Public Health Implications of SUID

- SUID rates comparable to birth defects mortality
  - About 4000 SUID deaths per year
  - About 2500 SIDS deaths per year
- SIDS (R95)
  - Leading cause of postneonatal mortality
  - Third leading cause of all infant mortality
- Accidental suffocation & strangulation in bed (W75)
  - Rates have more than tripled in last decade
  - 3.7 to 12.5 deaths per 100,000 live-births from 1995 to 2005
- Preventable Infant Mortality?

# Infant mortality rates due to SIDS, ASSB plus unknown cause, and total SUID, United States, 1990-2006



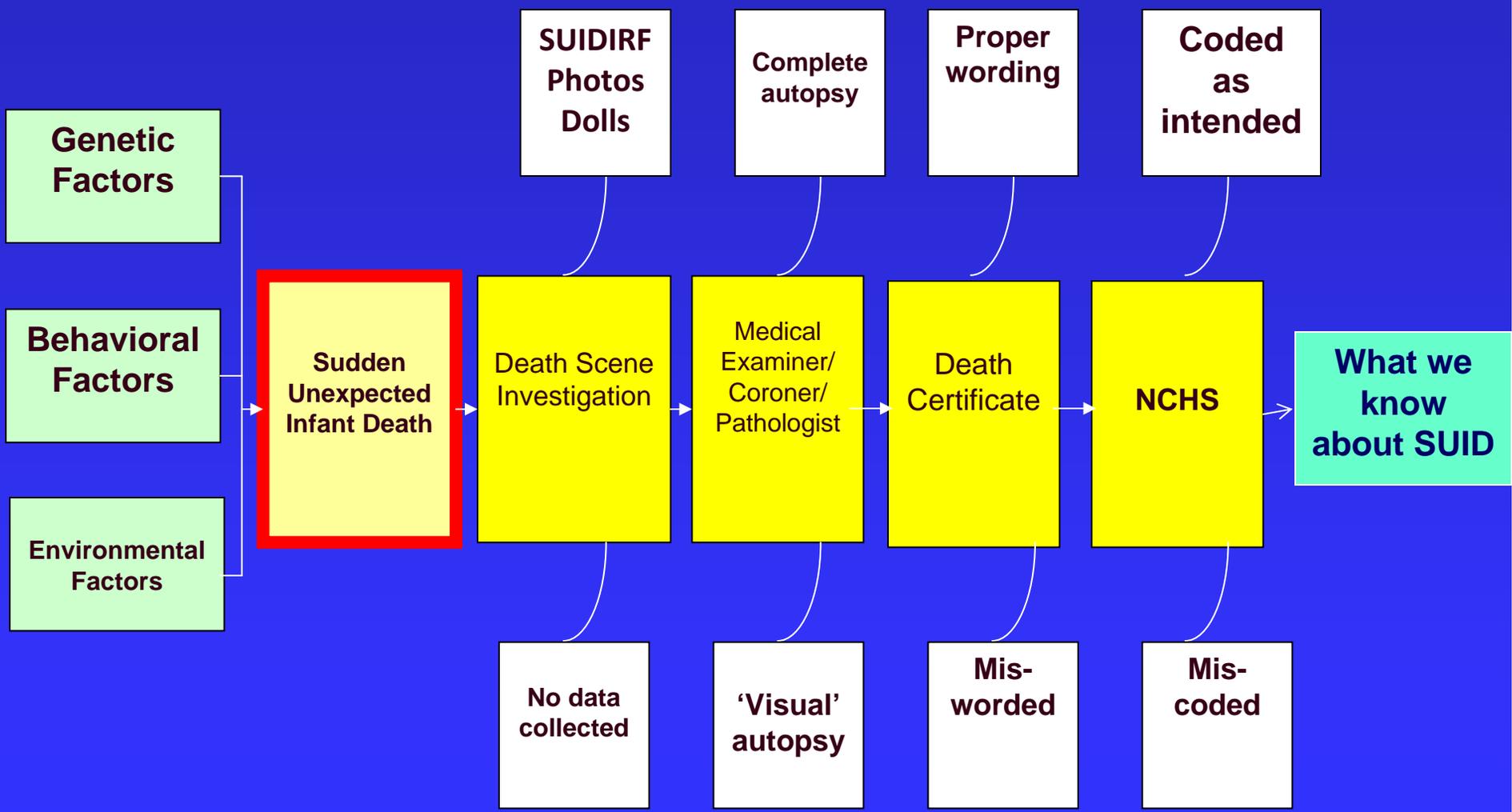
# What's wrong with current reporting and surveillance systems?

- Death certificates:
  - Describe infant demographics and cause of death
  - Don't mention the quality of the death scene investigation or if one was even done
  - Don't tell about the circumstances or factors that may have contributed to the SUID death
  - Text fields are limited
- Certifier's intended diagnosis is not clear
- Inconsistency in classification and reporting practices of death certifiers
- No information regarding the reliability or validity of the autopsy checkboxes on death certificate

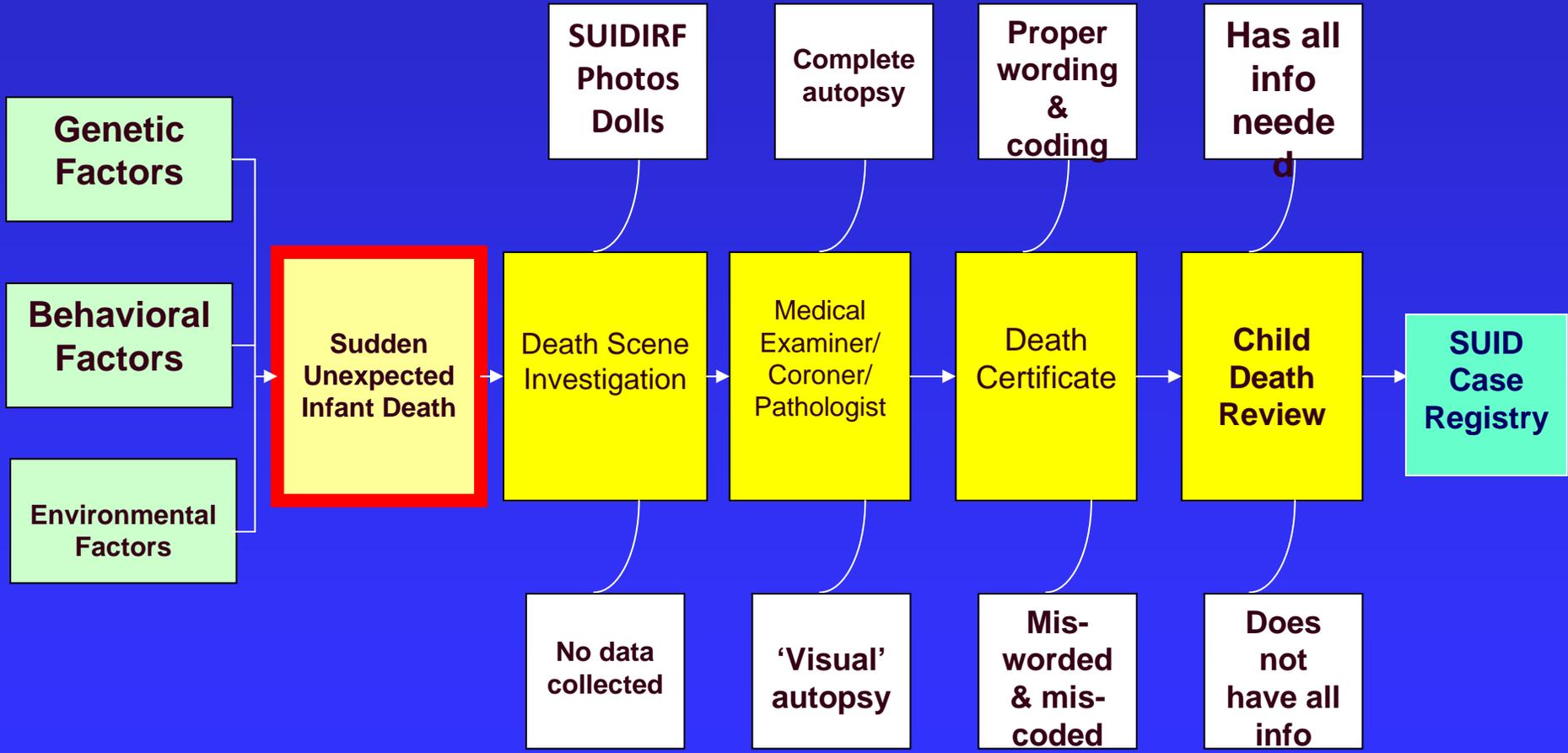
## List of terms that will be coded as a SIDS (R95) death when reported on the death certificate

- Cot Death
- Crib Death
- Sudden Death in Infancy or SDII
- Sudden Infant Death or SID
- Sudden Infant Death Syndrome or SIDS
- Sudden Unexplained Death or SUD
- Sudden Unexplained (Unexpected) Death in Infancy or SUDI
- **Sudden Unexplained Infant Death or SUID**
- Sudden plus (unexpected) or (unattended) or (unexplained)
- Death plus (cause unknown) or (in infancy) or (syndrome)
- Infant death plus (syndrome)
- Presumed SIDS
- Probably SIDS
- Consistent with SIDS
- Not SIDS

# Systems Influencing Accurate and Consistent Reporting and Classification



# Systems Influencing Accurate and Consistent Reporting and Classification



# Why do we need a registry?

- To accurately monitor cause specific SUID mortality and characteristics associated with deaths attributed to SUID
- To supplement death certificate data
  - Describe the quality of the death scene investigation
  - Describe the factors that may have contributed to the SUID death
- To use data to inform and evaluate prevention activities and potentially save lives

# Background

- 1996: First Sudden Unexplained Infant Death Investigation Reporting Form (SUIDIRF)
- 2005: Workgroups formed to update SUIDIRF and create curriculum
- 2006: Updated SUIDIRF released
- 2006-2008: SUIDI Training Academies
- 2006-2007: Feasibility Study
- 2008: Information Gathering Sessions

# Background

- National Information Gathering Sessions (2008)
  1. Designed program model
    - Do not duplicate efforts- build on CDR
    - Collaborate with Injury Prevention & MCH
    - Outlined 3 SUID-CR objectives
  2. Developed questions for a case registry
    - Individual based variables
    - System based variables
    - Funding announcement criteria outlined



**The Scene**



**The Pathologist**



**The Coroner/  
Medical Examiner**



**The Death Review**

SUIDI RF  
 EMS Run Reports  
 Law Enforcement  
 Death Scene  
 Interviews  
 Doll Reenactment  
 Photos

Autopsy Report  
 Toxicology Report

Death Certificate  
 ME/C report

CDR Case Report

**SUID Case Registry**

# Objectives

# Objectives of SUID Case Registry

1. Collect accurate and consistent information about the circumstances and events associated with SUID cases (Individual based variables)
2. Improve the quality and completeness of SUID data collection systems (System based variables)
3. Use sub-categories of SUID to increase knowledge of environmental and biologic factors associated with SUID (Categorization)

# 1. Individual Based Variables

- Partner driven questions
- Integrate into Case Reporting System v2.1S
- Types of new variables
  - Maternal health
  - Infant health
  - Sleep environment
  - Test results

## 2. Systems Based Variables

- Create 'completeness' checklists for death scene investigation and autopsy
- Measure quality of the system
- Integrate into Case Reporting System v2.1S
- Types of completeness information
  - Items available to medical examiner/coroner before determined COD
  - Tests and exams performed during autopsy

# 3. Categorization

- Used for our case registry purposes
  - Not to re-classify cause of death
- Analyzed and aggregated by CDC
- Based on information provided in CRS v2.1S
  1. Thoroughness of case investigation
  2. Factors that contributed to this death
  3. Certainty that factors contributed to death
  4. Mechanism of suffocation

# SUID Case Registry

- Built upon current Child Death Review:
  - Supplemental variables
    - Infant and maternal health status
    - Sleep environment
  - Systems checklists
    - Death scene information available before autopsy
    - Autopsy
    - Child Death Review
  - Categories based on thoroughness of case investigation, factors present and contributory status

# **SUID-CR Pilot Program**

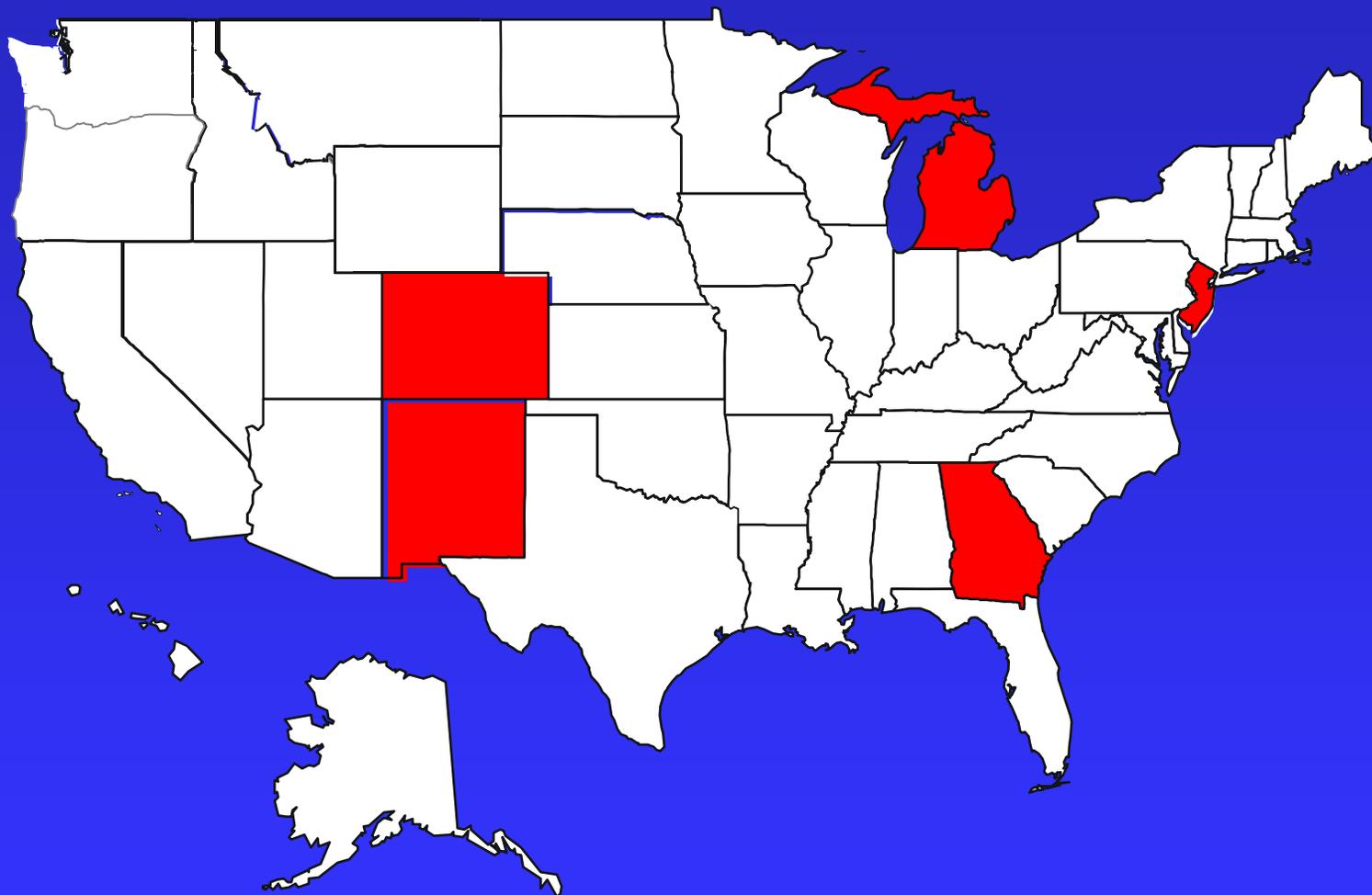
# Pilot Program

- Announced in March 2009
  - Criteria outlined by partners
- Closed in May 2009
  - 13 competitive proposals received
- Reviewed by objective team in June 2009
  - Scores, number of cases and population diversity were all considered
- Funded five states in August 2009

# Pilot Program

- Trained states in October 2009
- States trained local and state Child Death Review teams from October onward
- January 2010: Data collection begins
- April 2010: first quarterly report due
- September 2010: Reverse Site Visit to reflect upon and modify strategies

# SUID Case Registry Pilot States



# CDC SUID Initiative

Carrie Shapiro-Mendoza, PhD, MPH  
Lena Camperlengo, RN, MPH, DrPH(c)  
Shin Y. Kim, MPH  
Monica Murphy, MPH, PHPS Fellow  
Terry Njoroge, MPH  
Briana Lozano, MPH student

Centers for Disease Control and Prevention  
4770 Buford Highway, NE, Mailstop K-23  
Atlanta, Georgia 30341-3717  
770-488-6250

<http://www.cdc.gov/SIDS.htm>

- Disclaimer: The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention/the Agency for Toxic Substances and Disease Registry and should not be construed to represent any agency determination or policy.



SAFER • HEALTHIER • PEOPLE™



# You are the Death Certifier

Three month old Jane was alive at 3 AM when her mother woke up to breastfeed her. They had been asleep in the same bed since 11 PM. After breastfeeding, mom placed Jane on her back to sleep, with a pacifier in her mouth, on an adult queen sized mattress, between her and her husband at approximately 3:20 AM. Jane's father woke up at 6:30 AM, and discovered Jane unresponsive. The parents attempted CPR and called 911. Paramedics arrived in 12 minutes and also attempted to resuscitate Jane. Paramedics transported Jane to the local hospital, where she was pronounced dead.

Parents report that Jane was found by her father on her back between her mother and father and that she had been a healthy baby and never had been sick. A fitted sheet was secured on the bed and a light sheet was used for covering. An operating ceiling fan and open window provided ventilation in this apartment that was not air conditioned. Room temperature was estimated to be about 70 degrees. Parents report that Jane typically sleeps between them on this queen mattress and that they always place her to sleep on her back. Neither parent reports smoking. The bedroom appeared neat and clean.

Review of medical records – no relevant medical history

X-rays - negative

Toxicology screen - negative

Blood chemistry - negative

Microbiology results - negative

Sampled tissue of internal organs - no significance

# **SUID Case Registry Pilot Program Michigan**

A state's experience

Shannon M. Stotenbur-Wing, MSW  
Director, Child & Adolescent Health  
Michigan Public Health Institute