



National SIDS & Infant Death Program Support Center

1314 Bedford Avenue • Suite 210 • Baltimore, Maryland 21208

800-638-7437 • 410-415-6628 • FAX 410-415-5093

[www.sids-id-psc.org](http://www.sids-id-psc.org)

# Diagnosis Team

## *Summary of Actions and Recommendations*

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## **ORGANIZATION**

The National SIDS and Infant Death Program Support Center (NSIDPSC) formed in 1998 to provide information and assistance to national, state, and community organizations on sudden infant death syndrome (SIDS) and other types of infant death. The Center oversees eight work teams whose members serve on a volunteer basis and address the following areas: diagnosis, data and evaluation, bereavement, risk reduction, policy, training and education, information and technology, and underserved populations. The Center serves as a resource for professionals involved in scientific research and in provision of services for SIDS and infant death (SIDS/ID). Through the efforts of team members and staff, the Center produces new policies, tools, and recommendations to help train and educate those who interact with SIDS/ID families.

## **DIAGNOSIS TEAM**

The NSIDPSC Diagnosis Work Team consists of medical professionals who are mostly forensic pathologists, but some of whom practice pediatrics, neonatology, and family medicine. The team was formed with the purpose of providing technical assistance to medical examiners and coroners throughout the US at both the state and local level. Specifically, team members seek (1) to help improve the processes by which SIDS and other types of infant death are diagnosed and coded, (2) to promote better dissemination of diagnostic information to medical examiners, coroners, and others in the SIDS/ID field, and (3) to improve referral of families to services. At present, the team is focusing its efforts on refining methods of infant death scene investigation and reviewing the current legislation regulating autopsy and referral of families to services.

The Diagnosis work team recently reviewed a set of infant death scene investigation protocols submitted by state and county level medical examiner offices as well as the federal death scene investigation protocol developed by the Centers for Disease Control (CDC) entitled Sudden Unexplained Infant Death Investigation Report Form (SUIDIRF). Based on those reviews, the team created two categories of recommended protocols: a single protocol selected from among the NAME submissions, which would serve as a representative model of an acceptable format for those states that choose to develop their own forms for documenting infant death scene information; and the CDC protocol, which would be used as a working document and revised with modifications to make it more concise, clear and easy to use.

To initiate their review of death investigation protocols, team members posted a request on the listserv of the National Association of Medical Examiners (NAME), asking members to mail in examples of the infant death scene investigation protocols used in their offices and to specify whether the protocol was unique to their office or an adaptation of an existing form. In June 2000, the team met at the American Academy of Pediatrics in Elk Grove Village, IL to review the protocols that were submitted in response to that request. A total of 10 different protocols were submitted. Some offices responded by phone, indicating that they used the CDC SUIDIRF.

After completing its review of the ten protocols submitted by ME/C offices, the team selected the one from the Maine Office of the Chief Medical Examiner. This form was developed by the Maine State Police's Criminal Investigation Division and is used by the medical examiner's office to investigate infant deaths. Team members felt that this protocol allowed for the most concise yet thorough documentation of relevant aspects of the death scene and family history (such as the infant's last meal, type of bedding used, and substance abuse history of family members). The protocol has been posted on the NSIDPSC Web site.

During the June 2000 meeting, the team also prepared a summary report describing general recommendations for the determination of sudden infant death diagnoses. The Diagnosis team chose to use the CDC Sudden Unexplained Infant Death Investigative Report Form (SUIDIRF) as a working document, since many states have mandated its use for documenting infant deaths. Accordingly, the team reviewed the SUIDIRF and developed recommended modifications, categorizing each section of the tool according to its application to research purposes, its utility in aiding with diagnoses, and its usefulness in making referrals of families to services (see Appendix C). This document, complete with color-coded annotations and a description of the rationale behind the modifications, will be posted on the NSIDPSC Web site.



## **CODING AND CERTIFICATION OF INFANT DEATHS**

A critical need exists to provide death certifiers with a more precise system of coding sudden, unexplained infant deaths. Too often, discrepancies emerge between the terms that medical examiners and coroners use to classify different types of infant deaths. Failure to properly code a death could hinder the process of referring a bereaved family to the appropriate support services. The International Classification of Diseases, which was developed by the World Health Organization (WHO) and is administered through the National Center for Health Statistics (NCHS), is the official disease classification system used to provide mortality statistics for all causes of death in the US. The document, now in its tenth revision (ICD-10), is updated at regular intervals in order to remain current with advances in diagnostic technology and changes in medical terminology. The Diagnosis team has developed a revised set of diagnostic codes for the ICD-10 coding of sudden unexplained infant deaths. These revised codes have been submitted to WHO via NCHS and are presently under committee review. Pending approval of the document by all committees, team members will prepare a set of sample death scene scenarios to illustrate each of the new codes. Plans have also been made to seek endorsement and support for both the coding modifications and the revisions to the SUIDIRF from professional organizations such as NAME and the College of American Pathologists (CAP). Team members hope to present both documents at the next NAME board meeting in October 2001.

## **POLICY AND LEGISLATION**

At its most recent teleconference in April 2001, the team decided to collect ongoing information on legislation of death scene investigation and autopsy. NSIDPSC staff members frequently receive requests from SIDS parents, advocates, and others seeking information on policy and legislation that affect SIDS/ID diagnosis and service delivery. Accordingly, Diagnosis team members will work with members of the Policy team in order to gather and periodically review this information.

In the future, the team hopes to develop formal position statements addressing medical, epidemiological, and social issues that are relevant to diagnosis of SIDS and other types of infant death. Such topics could include: age outliers (those cases in which the infant's age falls outside the range defined for SIDS), the role of genetic and metabolic disorders in infant death, and cultural sensitivity issues in training death scene investigators, medical examiners, and others who interact with bereaved parents.

Training of coroners, medical examiners, death scene investigators and others involved in the investigation and certification of infant deaths remains a pressing issue. In the coming months, the team will collect and review existing training curricula and will develop new training materials based on these existing resources.

**APPENDIX A: TEAM MEMBERSHIP**

- Randy Hanzlick, MD, Fulton County Medical Examiner  
Atlanta, Georgia; *Interim Team Leader*
- Bruce Beckwith, MD, Loma Linda University  
Missoula, Montana
- Mary Dudley, MD, Coroner-Medical Examiner  
Wichita, Kansas
- Tracey Corey Handy, MD, Office of the Chief Medical Examiner  
Louisville, Kentucky
- Fern Hauck, MD, University of Virginia Health System  
Charlottesville, Virginia
- Maurice Ed Keenan, MD, American Academy of Pediatrics  
Cambridge, Massachusetts
- Boyd Stephens, MD, Chief Medical Examiner  
San Francisco, California
- Former member: John Smialek, MD, Chief Medical Examiner  
Baltimore, MD (*Deceased*)

**APPENDIX B: INFANT DEATH SCENE INVESTIGATION PROTOCOLS REVIEWED**

- Office of the Medical Examiner, Merced County, California
- Medical Examiner Office, San Diego, California
- Office of the Chief Medical Examiner, State of New Hampshire
- County of Winnebago Coroner's Office, Rockford, Illinois
- Office of the Chief Medical Examiner, State of Maine
- Office of the State Medical Examiner, State of New Jersey
- Office of the Medical Examiner, County of Delaware, Lima, Pennsylvania
- Office of the State Medical Examiner, Metro Nashville-Davidson County, Tennessee
- Minnehaha County Coroner, Sioux Falls, South Dakota
- Medical Examiner's Office, Pierce County, Tacoma, Washington

## **APPENDIX C: DIAGNOSIS TEAM MODIFICATIONS TO CDC SUIDIRF**

National SIDS & Infant Death Program Support Center

### **Diagnosis Work Team**

Annotated Recommendations for Modification to the  
CDC Sudden, Unexplained Infant Death Investigation Report Form  
(SUIDIRF 3.96)

#### **Color Key:**

Sections of the attached SUIDIRF are outlined in colors that designate their importance as categorized by the Work Team:

-  Not unique to infant death investigation and therefore removable from the SUIDIRF *as long as* the information is collected on other death investigation documents.
  -  Of primary interest to research and not needed to assist with diagnoses in a specific case, therefore removable from the SUIDIRF.
  -  Important to assist in making a diagnosis or for validating other information that may be useful for diagnosis, thereby justifying retention on the SUIDIRF.
  -  Desirable to retain on the SUIDIRF because the item fosters appropriate follow up services such as family counseling.
-  Numeric notations in each section correspond to specific textural and diagram recommendations made by the NSIDPSC Diagnosis work team.

## **Methodology/Rationale for Modifications**

Based upon review of numerous existing death investigation protocols, the NSIDPSC Diagnosis Work Team concluded:

- The content of investigative reports should take priority over the format in which information is collected.
- Many available protocols strive to collect similar information, and differences are often a matter of style rather than substance.
- There are some protocols that are more useful than others.
- A variety of available protocols should be made readily accessible to assist those who wish to use the protocols as they are or who wish to design their own protocol.
- Recommendations should concentrate on data items that are unique to infant death investigations and should assume that all items collected as a matter of routine in any death investigation (such as decedent's name, age, etc) need not be further discussed in this DWT Report. Such items have been documented in the literature.
- In order to develop a recommended minimum standard, the Diagnosis Work Team needed to select a single existing protocol as a working document and make recommendations to modify and improve upon that protocol.

In conjunction with the above conclusions, the DWT has selected as its working document the CDC Sudden Unexplained Infant Death Investigation Report Form (SUIDIRF).

The SUIDIRF was reviewed with the goal of allowing it to be shortened without significant sacrifice of practical and useful information. As stated above, it is not necessary to maintain the format of the SUIDIRF. The essential thing is to ensure inclusion of all of the necessary items, which could be collected in another format such as the CDC SUIDQUEST (an open ended questionnaire with more textual responses), or some similar format.

## **Recommended Modifications**

[See attached annotated SUIDIRF form]

### **Section I (Circumstances of Death):**

1. Eliminate Section I (Circumstances of Death) EXCEPT for the items in the boxes which include "Infant placed," "Known Alive," "Infant found," "First Response," "EMS Called," "EMS Response," and "Police Response"

### **Section II (Basic Medical Information):**

2. Reorder A, B, C so they are in logical sequence
3. Change "Number of Prenatal Visits" to "Where prenatal care was received."

4. After “Gestational age at birth,” specify that 40 weeks is considered full-term;
5. Add “During pregnancy, did the mother \_\_\_Smoke, \_\_Use Drugs, \_\_Drink Alcohol”
6. In R, change “Vaccination” to “Immunization”
7. In T, change to “Deceased siblings or death of related children”
8. Under “Medication History,” provide space to list medications (move it from where it is now to make the form flow better)

**Section III (Household Environment):**

9. In B., change “alcohol abuse” to “alcohol use” and, in C., change “drug abuse” to “drug use”
10. In I, delete words “or mold growth”
11. Delete prompts for “Number of Bedrooms,” “Estimated annual income,” “On Public Assistance”
12. Delete prompts for “Number of Adults,” “and children,” and “Total People”
13. Add prompt for “Does mother smoke?”
14. Delete all of the maternal information (marital status, education, etc.)

**Section IV (Infant and Environment):**

15. Add “Describe thickness of blankets”
16. Add “Describe clothing layer by layer”
17. Add “Was a cap/or hat worn by infant?”
18. Add “Was face covered by blankets?”
19. Add “Crib” to list of items that might be collected
20. Add “Head/Neck Position: \_\_Flexed \_\_Extended”
21. Add a place to indicate where, if other than the infant’s household, the environment being evaluated was located (such as “not at home—day care center”)

**Section V (Interview and Procedural Tracking):**

22. Add words “when appropriate” to “Cause of death discussed with family”
23. Delete “Detailed Protocol Completed” section

**Section VI (Overall Preliminary Summary)**

24. Keep as is

**Section VII (Case Disposition)**

25. Delete section entirely as information is available in other documents (i.e. law enforcement)

**Scene Diagram:**

26. In addition to Item 5, add a prompt to encourage recreation of the actual environmental conditions at the time the infant was discovered. This does *not* include, however, repositioning of the infant itself.
27. Add a place to diagram the infant in its immediate environment, such as the position in a crib.
28. Add prompt to recommend that, *if* the infant is still present in its original position, photographs should be taken.
29. Recommend that photos of a doll re-enactment be performed if infant is not in original position.

**Baby Diagram and SUIDIRF Supplement:**

30. Keep as is.

**Additional Recommendations:**

Items present in other investigative protocols that were thought to be of potential value for improving the SUIDIRF include:

- Indication of ventilation status in immediate area (windows open, etc.)
- Mother's maiden name and recent out of state residences to facilitate tracking/linkage to other births and deaths
- Specific comments about pacifier use and number
- Some statement about infant's motor skills and ability to lift head
- An indication of the usual sleep position
- Some indication of environmental cleanliness/hygiene
- Expansion of information about co-sleeping (how many, weight, etc.)
- Expand information on home/cultural/herbal remedies
- Add "was infant under anyone else's care in past 48 hours?"
- Clarify if "wrapped" means "swaddled"
- Add "any visible depressions or "pockets" in bedding or sleeping (supporting) surface
- Encourage the collection and attachment of EMT run sheets/police reports

**SUDDEN UNEXPLAINED INFANT DEATH  
INVESTIGATION REPORT FORM (SUIDIRF) 3.96**

Case number \_\_\_\_\_

Infant's full name _____	Age _____	DOB _____
Home address _____	Race _____	Sex _____
City, state, zip _____	Ethnicity _____	
County _____	SS# _____	
Police complaint number _____	Police department _____	

I. CIRCUMSTANCES OF DEATH				
Action	Date	Time	By whom (person or agency)	Remarks
ME/C notified				Receipt by:
NOK notified				Person:
Scene visit				____ ME/C staff ____ Other agency ____ Not done
Scene address				
Condition of infant when found	____ Dead (D) ____ Unresponsive (U) ____ In distress (I) ____ NA (N)			
Sequence of events before death:				

Recommended Deletion:  
Delete all sections *EXCEPT* **1**. All other information is available on – and may be cross-referenced from – other incident report forms.

Event	Date	Time	Location (street, city, state, county, zip)
Injury			
Discovery			
Arrival			Hospital: _____ Transport by: _____
Actual death			____ On scene (S) ____ Emergency room (E) ____ Inpatient (I) ____ En route or DOA (D) ____ During surgery (O)
Pronounced dead			By whom: _____ License #: _____ Where: _____

Event	Date	Time	By whom (person)	Remarks
Infant placed				Place:
Known alive				Place:
Infant found			<b>1</b>	Place:
First response				Type:
EMS called				From where:
EMS response			Agency:	
Police response			Agency:	

Place of fatal event ____ Witness in room or area (W) or ____ Unwitnessed (U) ____ At own home (H) or ____ Away from home (A) ____ Indoors (I) or ____ Outdoors (O) ____ In vehicle (V) or ____ Not in vehicle (N)	Describe type of place:
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**SUDDEN UNEXPLAINED INFANT DEATH  
INVESTIGATION REPORT FORM (SUIDIRF) 3.96**

Case number \_\_\_\_\_

II. BASIC MEDICAL INFORMATION				
Health care provider for infant:		Phone:		
Medical history	<input type="checkbox"/> Not investigated (X) <input type="checkbox"/> Unk (U) <input type="checkbox"/> No past problems (N) <input type="checkbox"/> Medical problems (P)			
Medical source	<input type="checkbox"/> Physician (P) <input type="checkbox"/> Other health care provider (H) <input type="checkbox"/> Other (O) <input type="checkbox"/> Medical records (M) <input type="checkbox"/> Family (F) <input type="checkbox"/> None (N)			
Specific infant medical history	Yes	No	Unk	Remarks
A. Problems during labor or delivery Birth hospital: Birth city and state:	2	5		Recommended Changes/Additions: 2 Items A, B, and C should be re-ordered to reflect chronological sequence (e.g. prenatal issues, labor/delivery, infant's history). 5 Add prompt for: "During pregnancy, did the mother ___ Smoke, ___ Use Drugs, ___ Drink Alcohol?"
B. Maternal illness or complications during pregnancy Number of prenatal visits:	3			
C. Major birth defects				
D. Infant was one of multiple births (e.g., a twin) Birth weight: Gestational age at birth (weeks):	4			
E. Hospitalization of infant after initial discharge				
F. Emergency room visits in past 2 weeks				
G. Known allergies				
H. Growth and weight gain considered normal				
I. Exposure to contagious disease in past 2 weeks				
J. Illness in past 2 weeks				
K. Lethargy, crankiness, or excessive crying in past 48 hours				
L. Appetite changes in past 48 hours				
M. Vomiting or choking in past 48 hours				
N. Fever or excessive sweating in past 48 hours				
O. Diarrhea or stool changes in past 48 hours				
P. Infant has ever stopped breathing or turned blue				
Q. Infant was ever breast-fed				
R. Vaccinations in past 72 hours	6			
S. Infant injury or other condition not mentioned above	7			
T. Deceased siblings				
Diet in past 2 weeks included: <input type="checkbox"/> Breast milk <input type="checkbox"/> Formula <input type="checkbox"/> Cow's milk <input type="checkbox"/> Solids				
Date and time of last meal: Content of last meal:				
Medication history	<input type="checkbox"/> Not investigated (X) <input type="checkbox"/> Unk (U) <input type="checkbox"/> Rx (P) <input type="checkbox"/> OTC (O) <input type="checkbox"/> Home remedies (H) <input type="checkbox"/> None (N)	8		
Emergency medical treatment	<input type="checkbox"/> None (N) <input type="checkbox"/> CPR (R) <input type="checkbox"/> Transfusion (T) <input type="checkbox"/> IV fluids (F) <input type="checkbox"/> Surgery (S)			
Medicine names and doses; if prescription, include Rx number, Rx date, and name of pharmacy:	Describe nature and duration of resuscitation and treatments used to revive infant:	Describe any known injuries or marks on infant created or observed during resuscitation or treatment:		

**SUDDEN UNEXPLAINED INFANT DEATH  
INVESTIGATION REPORT FORM (SUIDIRF) 3.96**

Case number \_\_\_\_\_

III. HOUSEHOLD ENVIRONMENT						
Action		Yes	No	Unk	Remarks	
A. House was visited						
B. Evidence of alcohol abuse						
C. Evidence of drug abuse						
D. Serious physical or mental illness in household						
E. Police have been called to home in past						
F. Prior contact with social services						
G. Documented history of child abuse						
H. Odors, fumes, or peeling paint in household						
I. Dampness, visible standing water, or mold growth						
J. Pets in household						
Type of dwelling:		Water source:		Number of bedrooms:		
Main language in home:		Estimated annual income:		On public assistance Yes No		
Number of adults (<18 years of age):		and children (<18 years of age):		living in household. Total = people.		
Number of smokers in household:		Does usual caregiver smoke? Yes No Unk		If yes, cigarettes/day		
Maternal information	Age:	Married (M)	Divorced (D)	Cohabiting w/partner:	Education (years):	Employed (E)
		Single (S)	Widowed (W)	Yes No		Not employed (N)

IV. INFANT AND ENVIRONMENT						
In crib (C) In bed (B)		Sleeping alone (A) NA (N)		Temperature of area:		
Other (O)		Sleeping with others (O)				
Body position when placed		Unk	Back	Stomach	Side	Other
Body position when found		Unk	Back	Stomach	Side	Other
Face position when found		Unk	To left	To right	Facedown	Face up To side
Nose or mouth was covered or obstructed		Unk	No	Yes		
Postmortem changes when found		Unk	None	Rigor	Lividity	Other
Number of cover or blanket layers on infant:		Covers on infant (C)		Wrapped (W)	No covers (N)	
Sleeping or supporting surface:		Clothing:				
Other items in contact with infant:		Items in crib or immediate environment:				
Devices operating in room:		Cooling source in room:		Heat source in room:		
		On (+) Central (C) None (N)		On (+) Central (C) None (N)		
		Off (-) Space (S)		Off (-) Space (S)		
Item collected	Yes	No	Item collected	Yes	No	Number of scene photos taken:
Baby bottle			Apnea monitor			Other items collected:
Formula			Medicines			
Diaper			Pacifier			
Clothing			Bedding			

Recommended Addition:  
 13 Add prompt for "Does mother smoke?"

Recommended Additions:

Add prompts for:

15 "Describe thickness of blankets"	18 "Was face covered by blankets?"
16 "Describe clothing layer by layer"	19 Include "Crib" in list of items that might be collected
17 "Was cap/hat worn by infant?"	20 "Head/Neck Position: ___ Flexed, ___ Extended"
21 Add a place to indicate where, if other than the infant's household, the environment being evaluated is located (such as "not at home - day care center.")	

**SUDDEN UNEXPLAINED INFANT DEATH  
INVESTIGATION REPORT FORM (SUIDIRF) 3.96**

Case number \_\_\_\_\_

V. INTERVIEW AND PROCEDURAL TRACKING					
Contact	Name	Date	Time	Phone	Relationship to infant
Mother					
Father					
Usual caregiver					
Last caregiver					
Placer					
Last witness					
Finder					
First responder					
EMS caller					
EMS responder					
Police					
Alternate contact person:			Phone:		
Action	Date	Time	Action		
Medical record review for infant			Doll reenactment performed ____ Yes ____ No		
Medical record review for mother			Scene diagram completed ____ Yes ____ No		
Physician or provider interview			Body diagram completed ____ Yes ____ No		
Referral to social or SIDS services			Detailed protocol completed ____ Yes ____ No ____ NA		
Cause of death discussed with family	22		Other: <span style="border: 1px solid yellow; padding: 2px;">23</span>		
VI. OVERALL PRELIMINARY SUMMARY					
Notes to pathologist performing autopsy:					
24					
Indications that an environmental hazard, drug, poison, or consumer product contributed to death ____ Yes ____ No			Organ or tissue donation requested by family or agency ____ Yes ____ No ____ Unk		
Cause of death: _____ Presumed SIDS _____ Suspect trauma or injury _____ Other					
VII. CASE DISPOSITION					
Case disposition	____ Case declined (D) due to Topic (T) _____ Locale (L)		____ Case accepted (J) for Autopsy (A) _____ Inspection (I) _____ Certification (C)		
Body disposition	____ Brought in for exam (E) _____ Brought in for holding or claim (C) _____ Released from site (R)				
Who will sign DC?					
Transport agent:	25	Funeral home:			
Investigator and affiliation:				Date:	
				Number of supplement pages attached:	

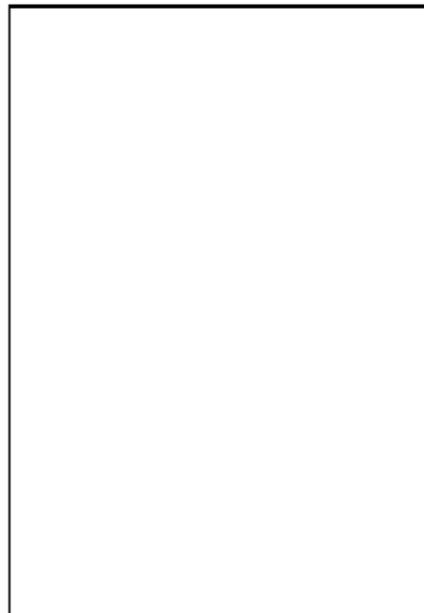
**SUDDEN UNEXPLAINED INFANT DEATH  
INVESTIGATION REPORT FORM (SUIDIRF) 3.96**

Case number \_\_\_\_\_

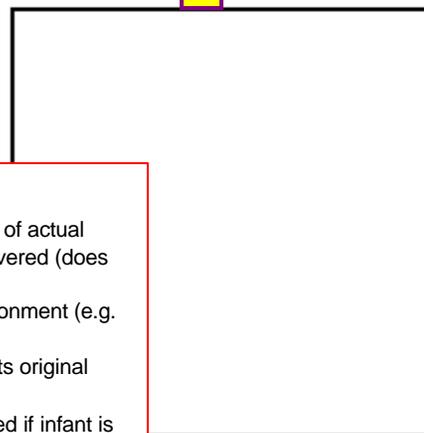
**SCENE DIAGRAM**

**Instructions**

- 1) Use figure at right for a rectangular room, and use figure below right for a square room. Use a supplementary page to draw an unusually shaped room.
- 2) Indicate the following on the diagram (check when done):
  - ..... North direction
  - ..... Windows and doors
  - ..... Wall lengths
  - ..... Ceiling height:
  - ..... Location of furniture
  - ..... Location of crib or bed
  - ..... Body location when found
  - ..... Location of other objects in room
  - ..... Location of heating and cooling supplies and returns
- 3) Make additional notes or drawings in available spaces as needed.
- 4) Check all that apply about heat source:
  - ..... Gas furnace or boiler
  - ..... Electric furnace or boiler
  - ..... Forced air
  - ..... Steam or hot water
  - ..... Electric baseboard
  - ..... Other: \_\_\_\_\_
  - ..... None
- 5) Complete the following:
  - Thermostat setting: \_\_\_\_\_
  - Thermostat reading: \_\_\_\_\_
  - Actual room temperature: \_\_\_\_\_
  - Outside temperature: \_\_\_\_\_



**27**



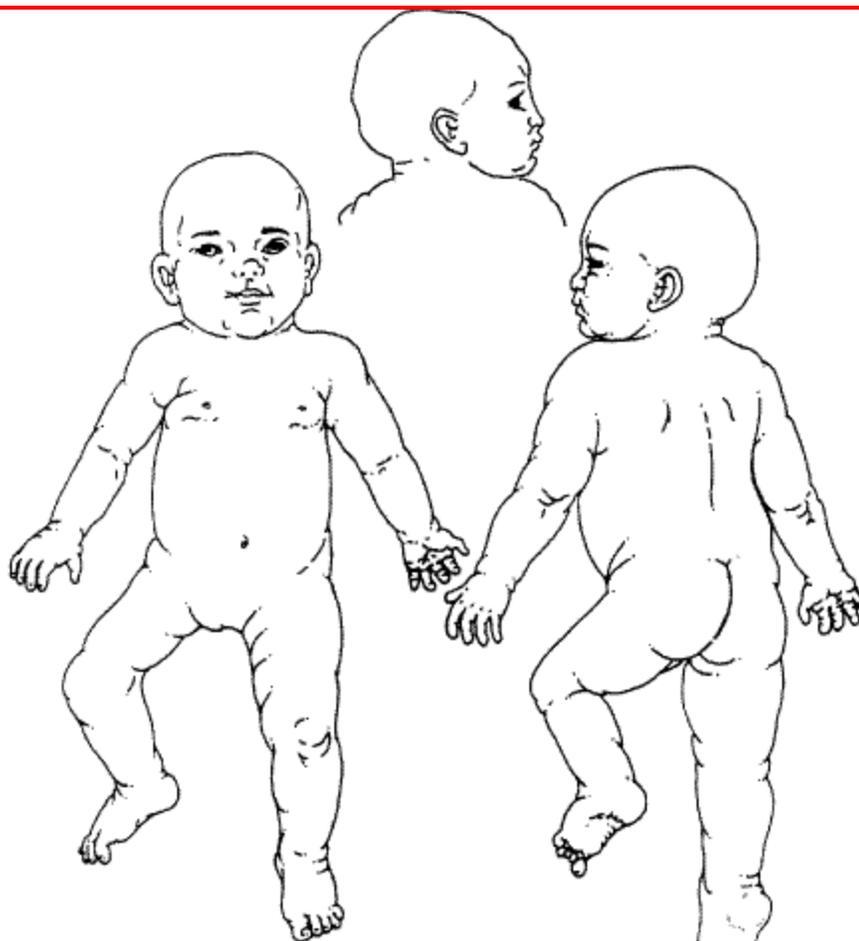
**26**

- Recommended Additions:**
- 26** In addition to item 5., add prompt to encourage recreation of actual environmental conditions at the time the infant was discovered (does not include re-positioning the infant itself).
  - 27** Add a diagram box where the infant in its immediate environment (e.g. position in crib) might be sketched.
  - 28** Add prompt to recommend that, *if* infant is still present in its original position, photos should be taken.
  - 29** Recommend that photos of doll re-enactment be performed if infant is not in original position.

SUDDEN UNEXPLAINED INFANT DEATH  
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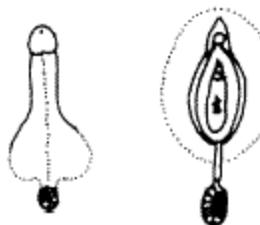
Case number \_\_\_\_\_

**BABY DIAGRAM**



**Instructions**

- 1) If present, indicate the following on the diagram. If not present, enter "None."
  - ..... Drainage or discharge from body or orifices
  - ..... Marks or bruises
  - ..... Location of diagnostic or therapeutic devices
  - ..... Pale pressure mark areas
  - ..... Predominate areas of lividity



- 2) Complete the following:
  - Body temperature: .....
  - Source of temperature: .....