SDY FIELD INVESTIGATION GUIDE AND FAMILY INTERVIEW TOOL

2.0 | 1.2017

This is as an optional tool to guide the information needed for the Sudden Death in the Young Case Registry Death Investigation and Family Interview. These questions mirror those in the Child Death Review Case Report and should be answered for sudden unexpected deaths in children in ages 0 through 19. It is important that you provide a copy of this tool to your Child Death Review Team, even if you were not able to obtain all the information. If the child whose death you are investigating is an infant (0 to 364 days old) also use the Sudden Unexplained Infant Death Investigation Reporting Form (SUIDIRF). http://www.cdc.gov/sids/suidrfdownload.htm

When introducing and using this tool, here are statements to share with families who are providing information: We would like to ask you additional questions about your child's and family's medical history. This information may assist the medical examiner/doctor in understanding why your child died. The questions are similar to what a doctor's office may ask you. This will take approximately 30-45 minutes. I understand that these questions may be difficult, or you may not know the answer, and that is ok. We can take breaks whenever you need. Would this be ok?

Some of the questions may not seem relevant or important since your child was so young. I still need to ask you to answer them the best you can. Even though it may not seem important, every little bit of information helps the medical examiner/doctor find out what happened. Remember it is okay to answer "I don't know."

We appreciate that this is a lot of information and we appreciate your time in helping us.

Name of person being interviewed: _____ Relationship to the deceased: _____

Name of Person conducting this interview: _____ Title: _____

Date/Time of Interview: _____ Signature: _____

Location of interview: _____ Interview Method (phone, in-person): _____

Medical records to collect

- ❑ Pediatric records for well and sick visits (including newborn screening results)
- ❑ If under 1 year of age, include mother's prenatal and obstetric reports
- ❑ Hospital birth records
- ❑ Emergency department records
- ❑ Emergency medical services/first responder records
- ❑ Immunization records
- ❑ Hospital records from day of death and from previous visits, if any
- ❑ Specialty health provider records (including any history of cardiac or neurological conditions)
- ❑ Any cardiac testing including previous electrocardiogram (EKG), echocardiogram, cardiac MRI, stress test, Holter monitors, and chest X-rays
- ❑ If child had epilepsy, records should include history of anti-epileptic drug levels, including frequency of monitoring of levels
- ❑ Any testing/records done as part of organ procurement
- ❑ Comprehensive family history records, if they exist

SDY

DATA COORDINATING CENTER FOR THE
SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

General Information

OVERLAPS SUIDIRF

Decedent Name: Decedent Date of Birth:

Decedent Gender: ❍ Male ❍ Female Decedent Ethnicity: ❍ Hispanic/Latino ❍ Non-Hispanic/Latino

Decedent Race: ❍ Black ❍ Asian, specify: ❍ American Indian, Tribe:
❍ Alaskan Native, Tribe: ❍ Pacific Islander, specify: ❍ Native Hawaiian

Decedent Next of Kin's Name: Decedent Next of Kin's Phone No:

Decedent Next of Kin's Email:

Date of Death: Time of Death:

Location of Death: Time Decedent Was Last Seen Alive:

Was the incident witnessed? ❑ Yes ❑ No ❑ Unknown If yes, by whom:

Was a death scene investigation performed? ❑ Yes ❑ No ❑ Unknown

If yes, check all that apply: ❑ CDC's SUIDI Reporting Form or jurisdictional equivalent ❑ Narrative description of circumstances
❑ Scene Photos ❑ Scene recreation with doll ❑ Scene recreation without doll ❑ Witness interviews

Activities within 24 hours of death

Child's activity at time of incident? Check all that apply.

❑ Sleeping ❑ Playing ❑ Working ❑ Eating ❑ Driving/vehicle occupant ❑ Unknown
❑ Other, specify:

Did the child experience any of the following stimuli at the time of incident or within 24 hours of incident? Check all that apply.

	at incident	within 24 hrs of incident
Physical activity	❑	❑
Sleep deprivation	❑	❑
Driving	❑	❑
Visual stimuli	❑	❑
Video game stimuli	❑	❑
Emotional stimuli	❑	❑
Auditory stimuli/startle (loud noises)	❑	❑
Physical trauma (direct blow to chest or head)	❑	❑

If yes to physical activity, specify:

❑ Other, specify:

❑ Unknown

Resuscitation

Resuscitation attempted?

❑ N/A ❑ Yes ❑ No ❑ Unknown

If yes, by whom?

If yes, type of resuscitation (CPR, Automated External Defibrillator (AED), rescue medications (e.g. atrophine, epinephrine, other), specify:

If no AED, was AED available/accessible? ❑ Yes ❑ No

If an Automated External Defibrillator (AED) was used, was a shock administered? ❑ Yes ❑ No

How many shocks?

If yes, what rhythm was recorded? (e.g. ventricular fibrillation)

Describe the death, including: time lapse between collapse, 911 call, access to CPR and automated external defibrillator, EMS arrival, defibrillation, transit to hospital, death, etc.

Symptoms within 72 hours of Death

check all that apply

Cardiac	Yes	No	Unknown
1. Chest pain	❑	❑	❑
2. Dizziness/lightheadedness	❑	❑	❑
3. Fainting	❑	❑	❑
4. Palpitations	❑	❑	❑
Neurologic			
5. Concussion	❑	❑	❑
6. Confusion	❑	❑	❑
7. Convulsions/seizure	❑	❑	❑
8. Headache	❑	❑	❑
9. Head injury	❑	❑	❑
10. Psychiatric symptoms	❑	❑	❑
11. Paralysis (acute)	❑	❑	❑
Respiratory			
12. Asthma	❑	❑	❑
13. Pneumonia	❑	❑	❑
14. Difficulty breathing	❑	❑	❑
Other Acute Symptoms			
15. Fever	❑	❑	❑
16. Heat exhaustion/heat stroke	❑	❑	❑
17. Muscle aches/cramping	❑	❑	❑
18. Slurred speech	❑	❑	❑
19. Vomiting	❑	❑	❑
20. Other, specify: _____			

Previous Serious Injury

check all that apply	Yes	No	Unknown
1. Near drowning	❑	❑	❑
2. Car accident	❑	❑	❑
3. Brain injury	❑	❑	❑
4. Other, specify: _____			

If yes, describe

_____

_____

_____

Symptoms prior to 72 hours of Death

check all that apply

Cardiac	Yes	No	Unknown
1. Chest pain	❑	❑	❑
2. Dizziness/lightheadedness	❑	❑	❑
3. Fainting	❑	❑	❑
4. Palpitations	❑	❑	❑
Neurologic			
5. Concussion	❑	❑	❑
6. Confusion	❑	❑	❑
7. Convulsions/seizure	❑	❑	❑
8. Headache	❑	❑	❑
9. Head injury	❑	❑	❑
Respiratory			
10. Difficulty breathing	❑	❑	❑
Other			
11. Slurred speech	❑	❑	❑
12. Other, specify: _____			

Exercise

Did the child ever have any of the following uncharacteristic symptoms during or within 24 hours after physical activity?

	Yes	No	Unknown
1. Chest pain	❑	❑	❑
2. Confusion	❑	❑	❑
3. Convulsions/seizure	❑	❑	❑
4. Dizziness/lightheadedness	❑	❑	❑
5. Fainting	❑	❑	❑
6. Headache	❑	❑	❑
7. Palpitations	❑	❑	❑
8. Shortness of breath/ difficulty breathing	❑	❑	❑
9. Other, specify: _____			
10. Unknown	❑	❑	❑

For children age 12 or older, did the child receive a pre-participation physical exam for a sport?

❑ N/A ❑ Yes ❑ No ❑ Unknown

If yes, date: _____

Restrictions? ❑ N/A ❑ Yes ❑ No ❑ Unknown

If yes, specify: _____

Medical History of Decedent - Symptoms/Medical History/Previous Injuries

Had the child ever been diagnosed by a medical professional for the following? Check all that apply.

Previous Diagnoses

	Yes	No	Unknown
Blood Disease			
1. Sickle cell disease	❑	❑	❑
2. Sickle cell trait	❑	❑	❑
3. Thrombophilia (clotting disorder)	❑	❑	❑
Cardiac			
4. Abnormal electrocardiogram (EKG or ECG)	❑	❑	❑
5. Aneurysm or aortic dilatation	❑	❑	❑
6. Arrhythmia/arrhythmia syndrome (irregular heart rhythm, palpitations) (DD: long QT, Brugada, CPVT, WPW)	❑	❑	❑
7. Cardiomyopathy (hypertrophic, dilated, arrhythmogenic right ventricular, left ventricular noncompaction)	❑	❑	❑
8. Commotio cordis (blow to chest causing cardiac arrest or death)	❑	❑	❑
9. Congenital heart disease	❑	❑	❑
10. Coronary artery abnormality	❑	❑	❑
11. Coronary artery disease (atherosclerosis)	❑	❑	❑
12. Endocarditis	❑	❑	❑
13. Heart failure	❑	❑	❑
14. Heart murmur	❑	❑	❑
15. High cholesterol	❑	❑	❑
16. Hypertension	❑	❑	❑
17. Myocarditis (heart infection)	❑	❑	❑
18. Pulmonary hypertension	❑	❑	❑
19. Sudden cardiac arrest	❑	❑	❑
Neurologic			
20. Anoxic brain Injury (injury caused by lack of oxygen to the brain)	❑	❑	❑
21. Traumatic brain injury/ head injury/concussion	❑	❑	❑
22. Brain tumor	❑	❑	❑
23. Brain aneurysm	❑	❑	❑
24. Brain hemorrhage	❑	❑	❑
25. Developmental brain disorder (cerebral palsy, structural brain malformation)	❑	❑	❑
26. Epilepsy/seizure disorder	❑	❑	❑
27. Febrile seizure	❑	❑	❑
28. Mesial temporal sclerosis	❑	❑	❑
29. Neurodegenerative disease	❑	❑	❑
30. Stroke/mini stroke/ TIA- Transient Ischemic Attack	❑	❑	❑
31. Central nervous system infection (meningitis or encephalitis)	❑	❑	❑
Respiratory			
32. Apnea	❑	❑	❑
33. Asthma	❑	❑	❑
34. Pulmonary embolism	❑	❑	❑
35. Pulmonary hemorrhage	❑	❑	❑
36. Respiratory arrest	❑	❑	❑
Other			
37. Connective tissue disease (Ehlers Danlos, Marfan syndrome, bicuspid aortic valve with aortic root dilation and/or cystic medial necrosis)	❑	❑	❑
38. Diabetes	❑	❑	❑
39. Endocrine disorder, other: thyroid, adrenal, pituitary	❑	❑	❑
40. Hearing problems or deafness	❑	❑	❑
41. Kidney disease	❑	❑	❑
42. Mental illness/ psychiatric disease	❑	❑	❑
43. Metabolic disease	❑	❑	❑
44. Muscle disorder or muscular dystrophy	❑	❑	❑
45. Oncologic disease treated by chemotherapy or radiation	❑	❑	❑
46. Prematurity	❑	❑	❑
47. Congenital disorder/ genetic syndrome	❑	❑	❑

48. Other, specify: _____

Follow-up Testing and Evaluation for Diagnosis

(e.g. echo, EKG, neuro eval)

If a more specific diagnosis is known, provide any additional information:

_____

Describe:

_____

_____

Routine treatment for diagnosis?

_____

_____

Medical History of Decedent - Symptoms/Medical History/Previous Injuries (circle all that apply)

Medications

In the 72 hours prior to death was the child taking any prescribed medication(s)?

❑ Yes ❑ No ❑ Unknown

If yes, describe:

_____

_____

Medication History

Was the child compliant with their prescribed medications?

_____

If not, describe why and how often:

_____

Recent medication changes? (extra doses, missed doses, change of medication)

_____

_____

❑ Unknown for all

Other Substances within 24 hours of Death

1. Over the counter (OTC) medicine
2. Recent/short term prescriptions (antibiotics)
3. Energy drinks
4. Caffeine
5. Performance enhancers
6. Diet assisting medications
7. Supplements
8. Tobacco (cigarettes, chewing, electronic/nicotine)
9. Alcohol
10. Illegal drugs (cocaine, heroin)
11. Legalized marijuana
12. Other, specify

If yes to any, describe:

_____

_____

Family History

Include information on 1st and 2nd degree relatives: *siblings, parents, grandparents, aunts, uncles and first cousins of the deceased as well as if they were older children if they had their own children.*

Family can be referred for genetic counseling at this center:

_____

_____

❑ Unknown for all

Sudden Death

1. Sudden, unexpected death before age 50, describe (SIDS, drowning, relative who died in single and/or unexplained motor vehicle accident (driver of car))

Heart Disease

1. Heart condition/heart attack or stroke before age 50
2. Aortic aneurysm or aortic rupture
3. Arrhythmia (fast or irregular heart rhythm)
4. Cardiomyopathy
5. Congenital heart disease

Neurologic Disease

1. Epilepsy or convulsions/seizure
2. Other neurologic disease

Symptoms

3. Febrile seizures
4. Unexplained fainting

Other

1. Congenital deafness
2. Connective tissue disease (Ehlers Danlos Syndrome, Marfan syndrome)
3. Mitochondrial disease
4. Muscle disorder or muscular dystrophy
5. Thrombophilia (clotting disorder)
6. Other diseases that are genetic or run in families

Genetic Testing

Has any blood relative (siblings, parents, aunts, uncles, cousins, grandparents) had genetic testing?

❑ Yes ❑ No ❑ Unknown

If yes, describe the results (disease, gene, mutation)

_____

_____

Epilepsy/Seizure Disorder

Answer only if child was diagnosed with an epilepsy/seizure disorder.

How old was the child when diagnosed with epilepsy/seizure disorder?

What was the underlying cause of the child's seizures? Check all that apply.

	Yes	No	Unknown
Brain injury/trauma	❑	❑	❑
Brain tumor	❑	❑	❑
Cerebrovascular	❑	❑	❑
Central nervous system infection	❑	❑	❑
Degenerative process	❑	❑	❑
Developmental brain disorder	❑	❑	❑
Inborn error of metabolism	❑	❑	❑
Genetic/chromosomal	❑	❑	❑
Mesial temporal sclerosis	❑	❑	❑
Idiopathic or cryptogenic	❑	❑	❑
Other acute illness or injury other than epilepsy, other, specify:	❑	❑	❑

What type(s) of seizures did the child have? Check all that apply.

	Yes	No	Unknown
Non-convulsive	❑	❑	❑
Convulsive (grand mal seizure or generalized tonic-clonic seizure)	❑	❑	❑
Occur when exposed to strobelights, video game, or flickering light (reflex seizure)	❑	❑	❑

Describe the child's epilepsy/seizures. Check all that apply.

	Yes	No	Unknown
Last less than 30 minutes	❑	❑	❑
Last more than 30 minutes (status epilepticus)	❑	❑	❑
Occur in the presence of fever (febrile seizure)	❑	❑	❑
Occur in the absence of fever	❑	❑	❑
Occur when exposed to strobe lights, video game, or flickering light (reflex seizure)	❑	❑	❑

How may seizures did the child have in the year preceding death?

Did treatment for seizures include anti-epileptic drugs?

If yes, how many different types of anti-epilepsy drugs (AED) did the child take?

Was night surveillance used?

SDY

DATA COORDINATING CENTER FOR THE
SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

Sudden Death in the Young Case Registry Data Coordinating Center
c/o Michigan Public Health Institute, 2479 Woodlake Circle, Okemos, MI 48864

Telephone: 800-656-2434 Email: info@SDYregistry.org
Web: www.sdyregistry.org Fax: 844-816-9662