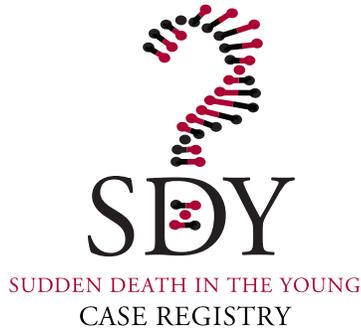


SUBJECT ID: _____



Instructions

This form can be used as a guide to the information needed for the Sudden Death in the Young Case Registry Death Investigation and Family Interview. Please keep a copy and provide a copy to the Child Death Review team reviewing this case. 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>

Name of Person conducting this interview: _____

Title: _____

Signature: _____

Date/Time of Interview: _____

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

General

Decedent Name: _____ Decedent Date of Birth: _____

Decedent Gender: Male Female Decedent Race: _____

Decedent Ethnicity: Hispanic/Latino Non-Hispanic/Latino

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

Date of Death: _____ Time of Death: _____

Location of Death: _____ Time Decedent Was Last Seen Alive: _____

Witnessed Event? Yes No If yes, by whom: _____

Was a Scene Investigation Completed? Yes No If yes, describe: _____

Activity at the time of collapse (sleep/rest/exercise/
within 24 hours of exercise/other stimuli)

Trigger or stimuli within 24 hours of collapse:

- 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)
- Other, specify: _____
- Unknown

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 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.

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

Symptoms within 72 hours of Death

Cardiac

- 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: _____

Symptoms prior to 72 hours of Death

Cardiac

- 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: _____

Previous Serious Injury

- 1. Near drowning
- 2. Car accident
- 3. Brain injury
- 4. Other, specify: _____

If yes, describe

Exercise

Symptoms during or within 24 hours after physical activity?

- 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 (circle all that apply)

Previous Diagnoses

Blood Disease

1. Sickle cell disease
2. Sickle cell trait
3. Thrombophilia

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
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)

Describe:

Routine treatment for diagnosis?

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

Medications

Medications within 72 hours of death?

Yes No Unknown

If yes, describe:

Medication History

Compliant? (if not, describe why and how often)

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

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

Family can be referred for genetic counseling at this center:

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

Did the decedent or any other family member have genetic testing done?

Yes No Unknown

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

Notes



SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

Sudden Death in the Young Case Registry Data Coordinating Center
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Okemos, MI 48864
Telephone: 800-656-2434 Email: info@SDYregistry.org Fax: 844-816-9662