

Attachment 7a: NCFRP Case Reporting System - SDY Module Section I

The screenshot displays a web browser window with the URL <https://data.nicfp.org/section1SDY/entry/201304>. The browser's address bar shows several open tabs, including "Home - Office of Re...", "CDR Case Reporting", "Travel", "SUIDSDY Registry SP", "Safe Sleep Environm...", "NIH SDY Research R...", "TA Tracker Form", and "SDY-R SP".

The main content area features the NCFRP logo (National Center for Fatality Review & Prevention) and a user login status: "Logged in as Meghan Faulkner. (CDR - Vermont) Logout".

On the left side, there is a "Case Sections" menu with the following items: # - Case Definition, A - Child Information, A1 - All Ages, B - Biological Parents, C - Primary Caregivers, D - Supervisor, E - Incident, F - Investigation, G - Cause of Death, I - Circumstances, I1 - SDY, I2 - Sleep Related, I3 - Consumer Product, I4 - Another Crime, I5-CAN/Supervision/Hazard, and J - Person Responsible.

The main content area shows a green notification box: "Case saved successfully". Below this is the title "CDR - Enter Case Information [47-01-2018-00012]" with a "Print this section" link. The section is titled "Section I1: Sudden and Unexpected Death in the Young".

Below the section title, there is a paragraph of text: "OMB No. 0920-1092, Exp. Date: 12/31/2018. Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-1092)".

Below the text, there is a question: "a. Was this death:" with two radio button options: "Homicide" and "Suicide". A "Deselect answer" link is located to the right of the options.

I. OTHER CIRCUMSTANCES OF INCIDENT - ANSWER RELEVANT SECTIONS

I1. SUDDEN AND UNEXPECTED DEATH IN THE YOUNG (SDY) This section displays online based on your state's settings.

Section I1: OMB No. 0920-1092, Exp. Date: 12/31/2018
 Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-1092)

a. Was this death:

- A homicide?
- A suicide?
- An overdose?
- A result of an external cause that was the obvious and only reason for the fatal injury?
- Expected within 6 months due to terminal illness?
- None of the above, go to I1b THIS IS AN SDY CASE
- Unknown, go to I1b

} If any of these apply, go to Section I2. THIS IS NOT AN SDY CASE.

b. Did the child have a history of any of the following acute conditions or symptoms within 72 hours prior to death? U/K for all

Symptom	Present w/in 72 hours of death			Other Acute Symptoms	Present w/in 72 hours of death			Symptom	Present more than 72 hours of death		
	Yes	No	U/K		Yes	No	U/K		Yes	No	U/K
Cardiac											
Chest pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Chest pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness/lightheadedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Heat exhaustion/heat stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Dizziness/lightheadedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fainting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Muscle aches/cramping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fainting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palpitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Slurred speech	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Palpitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurologic											
Concussion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concussion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Other, specify:	<input type="radio"/>			Confusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Convulsions/seizure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Convulsions/seizure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Headache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Head injury	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Head injury	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatric symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Respiratory			
Paralysis (acute)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Difficulty breathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respiratory											
Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Slurred speech	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pneumonia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>					Other, specify:	<input type="radio"/>		
Difficulty breathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								

d. Did the child have any prior serious injuries (e.g. near drowning, car accident, brain injury)? Yes No U/K If yes, describe:

e. Had the child ever been diagnosed by a medical professional for the following? U/K for all

Condition	Diagnosed			Condition	Diagnosed			Condition	Diagnosed						
	Yes	No	U/K		Yes	No	U/K		Yes	No	U/K				
Blood disease															
Sickle cell disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Anoxic brain injury	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Connective tissue disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Sickle cell trait	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Traumatic brain injury/	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Thrombophilia (clotting disorder)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	head injury/concussion				Endocrine disorder, other:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Cardiac															
Abnormal electrocardiogram (EKG or ECG)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Brain tumor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	thyroid, adrenal, pituitary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Aneurysm or aortic dilatation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Brain aneurysm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Hearing problems or deafness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Arrhythmia/arrhythmia syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Brain hemorrhage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Kidney disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Cardiomyopathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Developmental brain disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Mental illness/psychiatric disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Commotio cordis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Epilepsy/seizure disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Metabolic disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Congenital heart disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Febrile seizure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Muscle disorder or muscular dystrophy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Coronary artery abnormality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Mesial temporal sclerosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Oncologic disease treated by chemotherapy or radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Coronary artery disease (atherosclerosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Neurodegenerative disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Prematurity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Endocarditis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Stroke/mini stroke/	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Congenital disorder/genetic syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Heart failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	TIA-Transient Ischemic Attack				Other, specify:	<input type="radio"/>						
Heart murmur	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Central nervous system infection (meningitis or encephalitis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
High cholesterol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Respiratory											
Hypertension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Apnea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
Myocarditis (heart infection)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
Pulmonary hypertension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Pulmonary embolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
Sudden cardiac arrest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Pulmonary hemorrhage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
				Respiratory arrest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								

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

If any cardiac conditions above are selected, what cardiac treatments did the child have? Check all that apply: None

<input type="checkbox"/> Cardiac ablation	<input type="checkbox"/> Heart surgery	<input type="checkbox"/> Heart transplant
<input type="checkbox"/> Cardiac device placement (implanted cardioverter defibrillator (ICD) or pacemaker or Ventricular Assist Device (VAD))	<input type="checkbox"/> Interventional cardiac catheterization	<input type="checkbox"/> Other, specify: <input type="checkbox"/> U/K

f. Did the child have any blood relatives (brothers, sisters, parents, aunts, uncles, cousins, grandparents or other more distant relatives) with the following diseases, conditions or symptoms? U/K for all

<u>Y</u> <u>N</u> <u>U/K</u> Deaths	<u>Y</u> <u>N</u> <u>U/K</u> Symptoms
<input type="radio"/> <input type="radio"/> <input type="radio"/> Sudden unexpected death before age 50	<input type="radio"/> <input type="radio"/> <input type="radio"/> Febrile seizures
Heart Disease	<input type="radio"/> <input type="radio"/> <input type="radio"/> Unexplained fainting
<input type="radio"/> <input type="radio"/> <input type="radio"/> Heart condition/heart attack or stroke before age 50	Other Diagnoses
<input type="radio"/> <input type="radio"/> <input type="radio"/> Aortic aneurysm or aortic rupture	<input type="radio"/> <input type="radio"/> <input type="radio"/> Congenital deafness
<input type="radio"/> <input type="radio"/> <input type="radio"/> Arrhythmia (fast or irregular heart rhythm)	<input type="radio"/> <input type="radio"/> <input type="radio"/> Connective tissue disease
<input type="radio"/> <input type="radio"/> <input type="radio"/> Cardiomyopathy	<input type="radio"/> <input type="radio"/> <input type="radio"/> Mitochondrial disease
<input type="radio"/> <input type="radio"/> <input type="radio"/> Congenital heart disease	<input type="radio"/> <input type="radio"/> <input type="radio"/> Muscle disorder or muscular dystrophy
Neurologic Disease	<input type="radio"/> <input type="radio"/> <input type="radio"/> Thrombophilia (clotting disorder)
<input type="radio"/> <input type="radio"/> <input type="radio"/> Epilepsy or convulsions/seizure	<input type="radio"/> Other diseases that are genetic or run in families, specify:
<input type="radio"/> <input type="radio"/> <input type="radio"/> Other neurologic disease	

If sudden unexpected death before age 50, describe the type of event, which relative, and relative's age at death (for example, brother at age 30 who died in an unexplained motor vehicle accident (driver of car)):

g. Has any blood relative (siblings, parents, aunts, uncles, cousins, grandparents) had genetic testing?
 Yes No U/K

If yes, describe the test/gene tested, reason for testing, family member tested, and results:

Was a gene mutation found?
 Yes No U/K

h. In the 72 hours prior to death was the child taking any prescribed medication(s)?
 Yes No U/K
If yes, describe:

i. Within 2 weeks prior to death had the child:

	<u>N/A</u>	<u>Yes</u>	<u>No</u>	<u>U/K</u>
Taken extra doses of prescribed medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missed doses of prescribed medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changed prescribed medications, describe:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

j. Was the child compliant with their prescribed medications?
 N/A Yes No U/K
If not compliant, describe why and how often:

k. Was the child taking any of the following substance(s) within 24 hours of death?
Check all that apply:

<input type="checkbox"/> Over-the-counter medicine	<input type="checkbox"/> Supplements
<input type="checkbox"/> Recent/short term prescriptions	<input type="checkbox"/> Tobacco
<input type="checkbox"/> Energy drinks	<input type="checkbox"/> Alcohol
<input type="checkbox"/> Caffeine	<input type="checkbox"/> Illegal drugs
<input type="checkbox"/> Performance enhancers	<input type="checkbox"/> Legalized marijuana
<input type="checkbox"/> Diet assisting medications	<input type="checkbox"/> Other, specify: <input type="checkbox"/> U/K

If yes to any items above, describe:

l. Did the child experience any of the following stimuli at time of incident or within 24 hours of the incident? U/K for all at time of incident
 U/K for all within 24 hours of incident

Stimuli	At incident			Within 24 hrs of incident		
	Yes	No	U/K	Yes	No	U/K
Physical activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep deprivation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visual stimuli	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video game stimuli	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional stimuli	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Auditory stimuli/startle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical trauma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, specify:	<input type="radio"/>			<input type="radio"/>		

If yes to physical activity, describe type of activity:
At incident Within 24 hours of incident

Other specify:
At incident Within 24 hours of incident

m. Was the child an athlete? N/A Yes No U/K
If yes, type of sport: Competitive Recreational U/K
If competitive, did the child participate in the 6 months prior to death? Yes No U/K

n. Did the child ever have any of the following uncharacteristic symptoms during or within 24 hours after physical activity? Check all that apply:

<input type="checkbox"/> Chest pain	<input type="checkbox"/> Headache
<input type="checkbox"/> Confusion	<input type="checkbox"/> Palpitations
<input type="checkbox"/> Convulsions/seizure	<input type="checkbox"/> Shortness of breath/difficulty breathing
<input type="checkbox"/> Dizziness/lightheadedness	<input type="checkbox"/> Other, specify:
<input type="checkbox"/> Fainting	<input type="checkbox"/> U/K

If yes to any item, describe type of physical activity and extent of symptoms:

o. For child age 12 or older, did the child receive a pre-participation exam for a sport?
 N/A Yes No U/K
If yes:
Was it done within a year prior to death? Yes No U/K
Did the exam lead to restrictions for sports or otherwise? Yes No U/K
If yes, specify restrictions:

Questions p through v: Answer if "Epilepsy/Seizure Disorder" is answered Yes in question e above (Diagnosed for a medical condition)		
<p>p. How old was the child when diagnosed with epilepsy/seizure disorder?</p> <p>Age 0 (infant) through 20 years: _____</p> <p><input type="checkbox"/> U/K</p>	<p>r. What type(s) of seizures did the child have? Check all that apply:</p> <p><input type="checkbox"/> Non-convulsive</p> <p><input type="checkbox"/> Convulsive (grand mal seizure or generalized tonic-clonic seizure)</p> <p><input type="checkbox"/> Occur when exposure to strobe lights, video game, or flickering light (reflex seizure)</p> <p><input type="checkbox"/> U/K</p>	<p>t. How many seizures did the child have in the year preceding death?</p> <p><input type="radio"/> 0/never <input type="radio"/> 2 <input type="radio"/> More than 3</p> <p><input type="radio"/> 1 <input type="radio"/> 3 <input type="radio"/> U/K</p>
<p>q. What were the underlying cause(s) of the child's seizures? Check all that apply:</p> <p><input type="checkbox"/> Brain injury/trauma, specify: <input type="checkbox"/> Genetic/chromosomal</p> <p><input type="checkbox"/> Brain tumor <input type="checkbox"/> Mesial temporal sclerosis</p> <p><input type="checkbox"/> Cerebrovascular <input type="checkbox"/> Idiopathic or cryptogenic</p> <p><input type="checkbox"/> Central nervous system infection <input type="checkbox"/> Other acute illness or injury other than epilepsy</p> <p><input type="checkbox"/> Degenerative process <input type="checkbox"/> Other, specify:</p> <p><input type="checkbox"/> Developmental brain disorder <input type="checkbox"/> U/K</p> <p><input type="checkbox"/> Inborn error of metabolism</p>	<p>s. Describe the child's epilepsy/seizures (not including the seizure at time of death). Check all that apply:</p> <p><input type="checkbox"/> Last less than 30 minutes</p> <p><input type="checkbox"/> Last more than 30 minutes (status epilepticus)</p> <p><input type="checkbox"/> Occur in the presence of fever (febrile seizure)</p> <p><input type="checkbox"/> Occur in the absence of fever</p> <p><input type="checkbox"/> Occur when exposed to strobe lights, video game, or flickering light (reflex seizure)</p>	<p>u. Did treatment for seizures include anti-epileptic drugs?</p> <p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K</p> <p>If yes, how many different types of anti-epileptic drugs did the child take?</p> <p><input type="radio"/> 1 <input type="radio"/> 4 <input type="radio"/> More than 6</p> <p><input type="radio"/> 2 <input type="radio"/> 5 <input type="radio"/> U/K</p> <p><input type="radio"/> 3 <input type="radio"/> 6</p>
		<p>v. Was night surveillance used?</p> <p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K</p>