Instructions

This summary sheet of autopsy results should be completed following your investigation of a sudden and unexpected death in a child or youth under age 20. Once completed, please share this summary with your local or state Child Death Review Team for its SDY case review process. We hope you are able to participate in the reviews. Your jurisdiction is participating in the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, funded by the National Institutes of Health and the Centers for Disease Control and Prevention. The autopsy findings will be summarized with other case review information and biospecimen data (upon family consent) into the SUID and SDY Case Registry. Analysis of this comprehensive data will help us better understand the etiologies and risk factors for sudden death in the young.

Limited guidance is provided throughout this summary sheet in italics and footnotes. Please try to complete all elements by circling the appropriate responses and most importantly describing any abnormalities.

A longer and more detailed document called the SDY Autopsy Guidance is also available to you for further direction and instructions.

"Sudden" implies death within 24 hours of the first symptom, or those resuscitated from cardiac arrest and dying during the same hospital admission.

"Unexpected" refers to a death in someone who dies from an accidental injury or someone who was believed to have been in good health, or had a stable chronic condition or had an illness but death was not expected. Examples could include hypertrophic or dilated cardiomyopathy, congenital heart disease, epilepsy, asthma and pneumonia.

This summary, the guidance and instructions were developed by the SDY Autopsy Protocol Committee composed of medical examiners with experience in pediatric, cardiac and neuropathology, physician coroners, death investigators, and other medical professionals with experience in cardiology, neurology, emergency medicine, public health and genetics.

Inclusion and Exclusion Criteria

This autopsy results summary sheet is a key component of the SUID and SDY Case Registry and should be used for all cases that meet all of the following inclusion criteria and none of the following exclusion criteria:

Inclusion Criteria

Is the child under 20 years old?	❑ Yes, Include	❑ No, Exclude
Was the death sudden and unexpected and/or unwitnessed?	❑ Yes, Include	❑ No, Exclude

Exclusion Criteria

Was the death caused by an accident in which the external cause was the obvious and only reason* for the death?	❑ Yes, Exclude	❑ No, Include
*Exception: All infants under 1 year of age whose death was caused by suffocation		❑ Include
Was the death an obvious homicide?	❑ Yes, Exclude	❑ No, Include
Was the death an obvious suicide?	❑ Yes, Exclude	❑ No, Include
Was the death caused by an accidental or intentional overdose of drugs even if this caused cardiac or respiratory arrest?	❑ Yes, Exclude	❑ No, Include
Was the death caused by a terminal illness in which the death was reasonably expected to occur within 6 months?	❑ Yes, Exclude	❑ No, Include

SDY Autopsy Guidance and Instructions consulted?

❑ Yes ❑ No

Were additional specialists consulted on this autopsy (e.g., cardiac pathologist, neuropathologist)?

❑ Yes ❑ No

If yes, specify:

General

Sex: ❑ Male ❑ Female

Body weight:_____kg Body length:_____cm

Head circumference:_____cm

External Exam: If abnormalities suggestive of trauma, disease/syndrome, or medical intervention, please describe:

Photography (external) ❑ yes ❑ no

Imaging

(Circle all that were performed and describe the location)

X-Ray, single:

X-Ray, multiple views:

CT scan:

MRI:

Describe any abnormalities found on imaging:

Gross Examination of Organs

Organ	In situ exam	Gross weight of organ	Fixed or fresh (check)	Gross inspection (check box if normal; if not, describe abnormalities)	Sections retained[1]?
Brain (including leptomeninges)				❑ Normal	❑ Yes ❑ No
Neck structures[2]		Thyroid gland[3] Thymus	❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Body cavities[4]			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Heart			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Kidneys			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Liver			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Lungs			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Pancreas			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
Spleen			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No
GI tract			❑ Fresh ❑ Fixed	❑ Normal	❑ Yes ❑ No

[1]Small tissue samples in formalin.

[2]Neck structures include: epiglottis, aryepiglottic folds, arytenoid and thyroid cartilage to include the vocal cords, cricothyroid membrane, the cricoid cartilage and the tracheal rings, thyroid gland, strap muscles, and the vessels and nerves including those within the carotid sheath and tongue. Under 1 y.o. include the subglottic musculature.

[3]In infants the thyroid may be too small to weigh.

[4]Body cavities include the pleural, peritoneal and pericardial cavities and pelvis.

Detailed Review of Specified Organs

Thorax/Lungs

Aspiration

Pneumonia/consolidation ❑ Absent ❑ Present

Pulmonary artery thromboemboli[5] ❑ Absent ❑ Present (location): _____

Hemorrhage ❑ Absent ❑ Present

If present: Diffuse Focal, location: _____ Aspiration pattern (follows bronchi)

Pulmonary hypertension[6] ❑ Absent ❑ Present

Heart

Hemopericardium ❑ Absent ❑ Present

Vascular ring ❑ Absent ❑ Present

Right ventricular fat infiltration[7] ❑ Absent ❑ Present

If present, circle which wall ❑ Anterior ❑ Posterior Maximum % thickness of wall involved: _____

Right ventricular thinning[8] ❑ Anterior ❑ Posterior Location: _____

Hypertrophic cardiomyopathy ❑ Absent ❑ Present

Ventricular septal thickness[9]: _____ cm

Dilated cardiomyopathy ❑ Absent ❑ Present

Left ventricular noncompaction ❑ Absent ❑ Present

Restrictive cardiomyopathy ❑ Absent ❑ Present

Congenital heart disease[10,11] ❑ Absent ❑ Present (type) _____

Valve disease:

Mitral valve prolapse ❑ Absent ❑ Present

Valve stenosis ❑ Absent ❑ Present (location, severity) _____

Myocardial infarction (recent) ❑ Absent ❑ Present (location) _____

Coronary arteries: ❑ Ostia: ❑ Normal[12] ❑ Abnormal: (location)

Distribution: ❑ Normal, right dominant ❑ Normal, left dominant[13] ❑ Co-dominant

❑ Single ❑ Left anterior descending from right ❑ Circumflex from right

❑ Other: _____

Aneurysm: ❑ Absent ❑ Present

Dissection: ❑ Absent ❑ Present

Atherosclerosis: ❑ Absent ❑ Present

[5]If there is any question whether blood clots in the mainstem pulmonary artery branches are antemortem thromboemboli or postmortem clot, histology is definitive.

[6]Muscle layers in subpleural arterioles

[7]Concerning for arrhythmogenic right ventricular cardiomyopathy

[8]Concerning for arrhythmogenic right ventricular cardiomyopathy

[9]"Normal" includes origin of the conus artery adjacent to right coronary ostium (normal variant).

[10]Probe patent foramen ovale is considered a normal variant and should not be included under congenital heart disease.

[11]Surgical status will be recorded under evidence of cardiovascular interventions.

[12]"Normal" includes origin of the coronary artery adjacent to right coronary ostium (normal variant).

[13]The right coronary artery may be small in left-dominant hearts. Describe in further detail in "Other" section if absent/hypoplastic or if downstream sequelae exist (e.g., myocardial infarction).

Heart (continued)

Evidence of cardiovascular interventions ❑ Absent ❑ Present

Pacemaker (make, model, type)_____

Interrogated? ❑ Yes ❑ No Results: _____

Implanted defibrillator (make, model) _____

Interrogated? ❑ Yes ❑ No Results: _____

Implanted loop recorder (make, model) _____

Interrogated? ❑ Yes ❑ No Results: _____

Ventricular assist device (type, location) _____

Evidence of congenital heart surgery (type, location) _____

Stents/coils/plugs/occluder devices (type, location) _____

Prosthetic valves (type, location) _____

Other: _____

Brain

Dural sinus thrombosis ❑ Absent ❑ Present ❑ Sagittal ❑ Transverse

Epidural hemorrhage ❑ Absent ❑ Present

Subdural hemorrhage ❑ Absent ❑ Present ❑ Left ❑ Right ❑ Bilateral

If present: Amount:_____ml

Color: _____

Appearance: ❑ Clotted ❑ Liquid ❑ Shiny surface

Subarachnoid hemorrhage ❑ Absent ❑ Present

If present: Pattern: ❑ Diffuse ❑ Scattered ❑ Focal, location:_____

Severity: ❑ Mild ❑ Moderate ❑ Severe

Circle of Willis Distribution: ❑ Normal ❑ Abnormal:_____

Obstruction: ❑ Absent ❑ Present

Size: ❑ Normal ❑ Small ❑ Large ❑ Vessel(s):_____

Aneurysm: ❑ Absent ❑ Present

If present: Size:_____ mm Location:_____

Cingulate herniation ❑ Absent ❑ Present ❑ Right ❑ Left

Uncal herniation ❑ Absent ❑ Present ❑ Right ❑ Left ❑ Bilateral

Tonsillar herniation ❑ Absent ❑ Present ❑ Right ❑ Left ❑ Bilateral

❑ Chronic[14] ❑ Acute

Stroke ❑ Absent ❑ Present ❑ Location: _____

Heterotopia ❑ Absent ❑ Present ❑ Location: _____

Arterio-venous malformation ❑ Absent ❑ Present ❑ Location: _____

Compression of cerebral hemisphere ❑ Absent ❑ Present

Anoxic ischemic encephalopathy ❑ Absent ❑ Present

Other congenital anomalies of the brain ❑ Absent ❑ Present Describe: _____

[14]As in a malformation such as Arnold Chiari

Detailed Review of Specified Organs

Gastrointestinal Tract

Intussusception	❑ Absent	❑ Present
Obstruction	❑ Absent	❑ Present
Ruptured abdominal organ	❑ Absent	❑ Present
Volvulus	❑ Absent	❑ Present

Infectious Diseases

Epiglottitis	❑ Absent	❑ Present
Encephalitis	❑ Absent	❑ Present
Meningitis	❑ Absent	❑ Present
Myocarditis	❑ Absent	❑ Present
Endocarditis	❑ Absent	❑ Present
Pneumonia	❑ Absent	❑ Present
Urinary tract infection	❑ Absent	❑ Present

Tissue Sampling and Histology

Sampled Tissue	Number of Sections	Describe Abnormalities
Airways		
Brain including leptomeninges		
Heart		
Kidney		
Liver		
Lungs		
Pancreas		
Spleen		
Thymus		
Bone or costochondral tissue		Location: Abnormalities:
Endocrine organs[15]		
Gastrointestinal tract		

[15]Endocrine organs include: adrenal glands, pituitary gland, and the thyroid gland. The testes/ovaries can also be included.

Ancillary Testing

Testing	Describe Testing Performed	Results
	E.g. lab name and type of testing (toxicology panel or genetic testing for Long QT, etc...)	Circle Normal or Abnormal **If Abnormal, Describe**
Microbiology/cultures for infectious disease		❑ Normal ❑ Abnormal If abnormal, describe:
Postmortem metabolic screen		❑ Normal ❑ Abnormal If abnormal, describe:
Toxicology		❑ Normal ❑ Abnormal If abnormal, describe:
Vitreous testing		❑ Normal ❑ Abnormal If abnormal, describe:
Genetic testing		❑ Normal ❑ Abnormal If abnormal, describe:
Other, specify:		❑ Normal ❑ Abnormal If abnormal, describe:

Final Pathologic Diagnosis

Was the family referred to a tertiary care center with subspecialty expertise relevant to the cause of death (e.g. cardiology, neurology) for screening of at-risk relatives and genetic counseling?

❑ Yes ❑ No ❑ N/A

Where:

Notes

Sudden Death in the Young Case Registry Data Coordinating Center
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