



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 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 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. If you do not have a copy you can request one from your SDY State Coordinator.

“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 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? | <input type="checkbox"/> Yes, Include | <input type="checkbox"/> No, Exclude |
| Was the death sudden and unexpected and/or unwitnessed? | <input type="checkbox"/> Yes, Include | <input type="checkbox"/> No, Exclude |

Exclusion Criteria

- | | | |
|---|---------------------------------------|--------------------------------------|
| Was the death caused by an accident in which the external cause was <u>the obvious and only</u> reason* for the death? | <input type="checkbox"/> Yes, Exclude | <input type="checkbox"/> No, Include |
| *Exception: All infants under 1 year of age whose death was caused by suffocation | | <input type="checkbox"/> Include |
| Was the death an obvious homicide? | <input type="checkbox"/> Yes, Exclude | <input type="checkbox"/> No, Include |
| Was the death an obvious suicide? | <input type="checkbox"/> Yes, Exclude | <input type="checkbox"/> No, Include |
| Was the death caused by an accidental or intentional overdose of drugs even if this caused cardiac or respiratory arrest? | <input type="checkbox"/> Yes, Exclude | <input type="checkbox"/> No, Include |
| Was the death caused by a terminal illness in which the death was reasonably expected to occur within 6 months? | <input type="checkbox"/> Yes, Exclude | <input type="checkbox"/> 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) | | | | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Neck structures ² | | Thyroid gland ³ Thymus | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Body cavities ⁴ | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Heart | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Kidneys | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Liver | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Lungs | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Pancreas | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Spleen | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| GI tract | | | <input type="checkbox"/> Fresh <input type="checkbox"/> Fixed | <input type="checkbox"/> Normal | <input type="checkbox"/> Yes <input type="checkbox"/> No |

¹Small tissue samples in formalin.²Neck 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.³In infants the thyroid may be too small to weigh.⁴Body cavities include the pleural, peritoneal and pericardial cavities and pelvis.

Detailed Review of Specified Organs**Thorax/Lungs**

Aspiration

- Pneumonia/consolidation Absent Present
- Pulmonary artery thromboemboli⁵ Absent Present (location): _____
- Hemorrhage Absent Present
- If present: Diffuse _____ Focal, location: _____ Aspiration pattern (follows bronchi)
- Pulmonary hypertension⁶ Absent Present

Heart

- Hemopericardium Absent Present
- Vascular ring Absent Present
- Right ventricular fat infiltration⁷ Absent Present
- If present, circle which wall Anterior Posterior Maximum % thickness of wall involved: _____
- Right ventricular thinning⁸ Anterior Posterior Location: _____
- Hypertrophic cardiomyopathy Absent Present
- Ventricular septal thickness⁹: _____ 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: Normal¹² Abnormal: (location) _____
- Distribution: Normal, right dominant Normal, left dominant¹³ Co-dominant
- Single Left anterior descending from right Circumflex from right
- Other: _____
- Aneurysm: Absent Present
- Dissection: Absent Present
- Atherosclerosis: Absent Present

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

⁶Muscle layers in subpleural arterioles

⁷Concerning for arrhythmogenic right ventricular cardiomyopathy

⁸Concerning for arrhythmogenic right ventricular cardiomyopathy

⁹“Normal” includes origin of the conus artery adjacent to right coronary ostium (normal variant).

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

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

¹²“Normal” includes origin of the coronary artery adjacent to right coronary ostium (normal variant).

¹³The 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: _____

BrainDural sinus thrombosis Absent Present Sagittal TransverseEpidural hemorrhage Absent PresentSubdural hemorrhage Absent Present Left Right Bilateral

If present: Amount: _____ ml

Color: _____

Appearance: Clotted Liquid Shiny surfaceSubarachnoid hemorrhage Absent PresentIf present: Pattern: Diffuse Scattered Focal, location: _____Severity: Mild Moderate SevereCircle of Willis Distribution: Normal Abnormal: _____Obstruction: Absent PresentSize: Normal Small Large Vessel(s): _____Aneurysm: Absent Present

If present: Size: _____ mm Location: _____

Cingulate herniation Absent Present Right LeftUncal herniation Absent Present Right Left BilateralTonsillar herniation Absent Present Right Left Bilateral Chronic¹⁴ AcuteStroke Absent Present Location: _____Heterotopia Absent Present Location: _____Arterio-venous malformation Absent Present Location: _____Compression of cerebral hemisphere Absent PresentAnoxic ischemic encephalopathy Absent PresentOther congenital anomalies of the brain Absent Present Describe: _____¹⁴As 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 | | |

¹⁵Endocrine 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 | | <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal If abnormal, describe: |
| Postmortem metabolic screen | | <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal If abnormal, describe: |
| Toxicology | | <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal If abnormal, describe: |
| Vitreous testing | | <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal If abnormal, describe: |
| Genetic testing | | <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal If abnormal, describe: |
| Other, specify: | | <input type="checkbox"/> Normal <input type="checkbox"/> 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

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