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? □ 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 Summary**

**Subject ID:**

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**SDY Autopsy Guidance and Instructions consulted?**

- [ ] Yes  
- [x] No

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

- [ ] Yes  
- [ ] No

If yes, specify:

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**General**

- **Sex:**  
  - [ ] Male  
  - [x] Female

- **Body weight:** [ ] kg  
  - **Body length:** [ ] cm

- **Head circumference:** [ ] cm

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

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**Photography (external)**

- [ ] yes  
- [ ] no

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**Imaging**

(Circle all that were performed and describe the location)

- **X-Ray, single:**

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- **X-Ray, multiple views:**

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- **CT scan:**

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- **MRI:**

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**Describe any abnormalities found on imaging:**

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### Gross Examination of Organs

<table>
<thead>
<tr>
<th>Organ</th>
<th>In situ exam</th>
<th>Gross weight of organ</th>
<th>Fixed or fresh (check)</th>
<th>Gross inspection (check box if normal; if not, describe abnormalities)</th>
<th>Sections retained?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain (including leptomeninges)</td>
<td></td>
<td></td>
<td></td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Neck structures&lt;sup&gt;2&lt;/sup&gt;</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Thyroid gland&lt;sup&gt;3&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thymus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body cavities&lt;sup&gt;4&lt;/sup&gt;</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Heart</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Kidneys</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Lungs</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Pancreas</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Spleen</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>GI tract</td>
<td></td>
<td></td>
<td>☐ Fresh ☐ Fixed</td>
<td>☐ Normal</td>
<td>☐ Yes ☐ No</td>
</tr>
</tbody>
</table>

<sup>1</sup>Small tissue samples in formalin.

<sup>2</sup>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.

<sup>3</sup>In infants the thyroid may be too small to weigh.

<sup>4</sup>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  
  - Absent □  
  - Present □  
  - Present (location):  
- Hemorrhage  
  - Absent □  
  - Present □  
  - If present: Diffuse  
  - Focal, location:  
  - Aspiration pattern (follows bronchi)  
- Pulmonary hypertension  
  - Absent □  
  - Present □

### Heart

**Hemopericardium**  
- Absent □  
- Present □

**Vascular ring**  
- Absent □  
- Present □

**Right ventricular fat infiltration**  
- Absent □  
- Present □  
- If present, circle which wall  
  - Anterior □  
  - Posterior □  
  - Maximum % thickness of wall involved:  

**Right ventricular thinning**  
- Absent □  
- Present □  
- Location:  

**Hypertrophic cardiomyopathy**  
- Absent □  
- Present □

**Ventricular septal thickness**  
- Absent □  
- Present □

**Dilated cardiomyopathy**  
- Absent □  
- Present □

**Left ventricular noncompaction**  
- Absent □  
- Present □

**Restrictive cardiomyopathy**  
- Absent □  
- Present □

**Congenital heart disease**  
- 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 □
  - Abnormal: (location) □
- Distribution:  
  - Normal, right dominant □
  - Normal, left dominant □
  - Co-dominant □
  - Single □
  - Left anterior descending from right □
  - Circumflex from right □
- Other:  
  - Absent □  
  - Present □
- Aneurysm:  
  - Absent □  
  - Present □
- Dissection:  
  - Absent □  
  - Present □
- Atherosclerosis:  
  - Absent □  
  - Present □

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1. If there is any question whether blood clots in the mainstem pulmonary artery branches are antemortem thromboemboli or postmortem clot, histology is definitive.
2. Muscle layers in subpleural arterioles
3. Concerning for arrhythmogenic right ventricular cardiomyopathy
4. Concerning for arrhythmogenic right ventricular cardiomyopathy
5. Normal includes origin of the conus artery adjacent to right coronary ostium (normal variant).
6. Probe patent foramen ovale is considered a normal variant and should not be included under congenital heart disease.
7. Surgical status will be recorded under evidence of cardiovascular interventions.
8. Normal includes origin of the coronary artery adjacent to right coronary ostium (normal variant).
9. 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 □ 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:  

As in a malformation such as Arnold Chiari
## Detailed Review of Specified Organs

### Gastrointestinal Tract

<table>
<thead>
<tr>
<th>Condition</th>
<th>Present</th>
<th>Absent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intussusception</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obstruction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ruptured abdominal organ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volvulus</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Infectious Diseases

<table>
<thead>
<tr>
<th>Condition</th>
<th>Present</th>
<th>Absent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epiglottitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encephalitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meningitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myocarditis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endocarditis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Tissue Sampling and Histology

<table>
<thead>
<tr>
<th>Sampled Tissue</th>
<th>Number of Sections</th>
<th>Describe Abnormalities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airways</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain including leptomeninges</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lungs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spleen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thymus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone or costochondral tissue</td>
<td>Location:</td>
<td>Abnormalities:</td>
</tr>
<tr>
<td>Endocrine organs(^1)</td>
<td>Location:</td>
<td>Abnormalities:</td>
</tr>
<tr>
<td>Gastrointestinal tract</td>
<td>Location:</td>
<td>Abnormalities:</td>
</tr>
</tbody>
</table>

\(^1\)Endocrine organs include: adrenal glands, pituitary gland, and the thyroid gland. The testes/ovaries can also be included.
## Ancillary Testing

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

### 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: