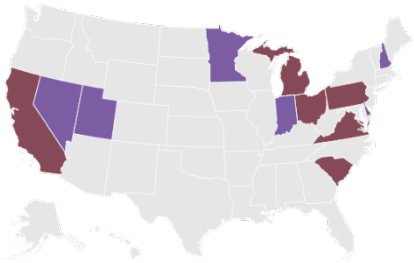
SUID and SDY Case Registry Summary for Medical Examiners and Coroners

Criteria



Sudden and unexpected deaths in residents of funded states and jurisdictions are eligible for participation in the SDY component of the SUID and SDY Case Registry. Recipients on the map of the states and jurisdictions are funded to participate from September 30, 2023-2028.

Click the image to view our interactive map, which highlights participating states and regions.

The following recipients are funded for SDY activities statewide: Delaware, Indiana, Minnesota, Nevada, New Hampshire, and Utah. These recipients are funded for SDY activities in jurisdictions: Charleston, South Carolina; Hamilton County, Ohio; San Francisco County, California; and select counties in Michigan, Pennsylvania, and Virginia.

Inclusion criteria - At the time of death, the death presented as sudden and unexpected, and the child was < 20 years of age and a resident of the funded state/jurisdiction.

Exclusion criteria - homicide, suicide, intentional overdose of drugs or terminal illness in which the death was reasonably expected to occur within 6 months.

Medical Examiners/Pathologists in Funded Jurisdictions

- Incorporate the Case Registry investigation and autopsy tools into office protocols.
- At the time of autopsy, collect biospecimens: K2EDTA blood and fresh frozen tissue.
- If you have questions on the next steps for saved samples, contact the SUID and SDY Case Registry Data Coordinating Center.

Medical Examiners/Pathologists that are not in Funded Jurisdictions

- Incorporate the Case Registry investigation and autopsy tools to promote standardization in autopsy and investigation of young sudden deaths.
- If you would like to offer the family DNA banking or diagnostic genetic testing, the best samples to collect at the time of autopsy are K2EDTA blood and fresh frozen tissue.
- If you have questions on the next steps for saved samples, contact the SUID and SDY Case Registry Data Coordinating Center.

Purpose

The SUID (Sudden Unexpected Infant Death) and SDY (Sudden Death in the Young) Case Registry serves as an important resource for families coping with the sudden loss of a child. This registry compiles information about young individuals who pass away unexpectedly. It includes infants, children, and young adults up to the age of 20.

Death investigators face challenges in pinpointing the reasons behind sudden deaths in young people. Similarly, public health agencies struggle to accurately tally the occurrences of these tragic events. As a result, doctors, scientists, and grieving families lack a comprehensive understanding of how frequently these deaths occur and what factors contribute to them.

The Case Registry aims to address these gaps.

Goals

By systematically collecting and storing information related to sudden child deaths, the SUID and SDY Case Registry serves several crucial purposes:

- Counting and categorizing deaths
- Investigate causes and risk factors
- Preventing future tragedies

Consent is coordinated by each funded state or jurisdiction. Consent from the child's legally authorized representative or next of kin is needed for extracted DNA to be used in research and/or DNA banking.

For Child Death Review Teams
Encourage your team to complete the SUID and SDY Case Registry variables in the Pediatric National Fatality Review Case Reporting System – they are accessible to all teams, even if they are not funded for the Case Registry.

For Families

- At time of death investigation/ consent, families will be informed about local and national resources for bereavement and family medical follow-up
- Families can consent to free DNA banking and/or research genetic testing (genome)
- Actionable results from research will be CLIA confirmed