



DATA COORDINATING CENTER FOR THE
SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

Primary Investigator

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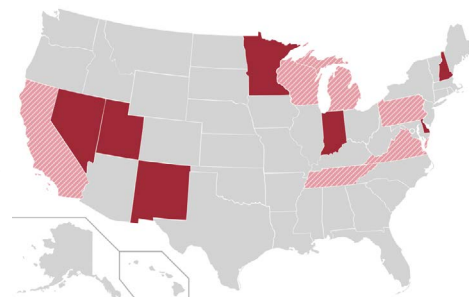
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IRB approval through MPHI Centralized IRB

www.sdyregistry.org

Criteria

Sudden and unexpected deaths in residents of funded states and jurisdictions are eligible for participation in the SDY Case Registry. Awardees on the map of the states and jurisdictions are funded to participate in the SDY Case Registry from September 30, 2018-2023.

Click the image to see our interactive map and see participating states and regions. ►



The following awardees are funded for SDY statewide: Delaware, Indiana, Minnesota, Nevada, New Hampshire, New Mexico, and Utah. Awardees funded for jurisdictions for SDY include: San Francisco County (CA), select counties in Michigan, Pennsylvania, Tennessee, Virginia and Wisconsin.

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

- Use the [SDY Case Registry investigation and autopsy tools](#)
- At the time of autopsy, collect biospecimens: K2EDTA blood or fresh frozen tissue
- If you have questions on next steps for saved samples contact the SDY Case Registry

Medical Examiners/Pathologists that are not in Funded Jurisdictions

- Use the SDY 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 or fresh frozen tissue
- If you have questions on next steps for saved samples contact the SDY Case Registry

Purpose

The Sudden Death in the Young (SDY) Case Registry gathers information to learn more about young people who die suddenly and unexpectedly. Babies, children and young adults up to age 20 are included in the SDY Case Registry. The cause of these deaths is not always able to be determined. It has also been hard for public health agencies to count the true numbers of these deaths. This means that doctors, scientists and families really do not have a good understanding of how often these deaths happen and what causes these deaths, which makes similar deaths more difficult to prevent.

Goals

The SDY Case Registry gathers and stores information about sudden child deaths to help:

- Count the number and types of sudden deaths in babies, children and young adults up to age 20
- Try to understand the causes for the deaths
- See if some children are more at risk of dying than others
- Find ways to prevent these deaths

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 Death Review Teams

Encourage your Child Death Review team to complete the SDY Case Registry variables in the Child Fatality Review Case Reporting System – they are accessible to all teams, even if they are not funded for the SDY 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 CLIA DNA banking and/or research genetic testing (genome)
- Actionable results from research will be CLIA confirmed