**High-level overview of Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) findings**

## Goals of the SUID and SDY Case Registry

The goals are to count the number of cases, understand the causes and risk factors, and inform prevention strategies for infants, children, and young adults who die suddenly and unexpectedly. The Case Registry has and will continue to publish incidence calculated through this project. The states and jurisdictions participating gather data and consented DNA samples. Approved researchers study the data and DNA to learn more about sudden death in the young.

## History

- 2006 Feasibility study concludes the Child Death Review system was best suited to supply the level of detailed contextual information on SUID needed for the registry.
- 2008 CDC begins conversations with the HRSA funded National Center for Fatality Review and Prevention to build the registry on the existing Child Death Review system and the National Fatality Review Case Reporting System (NFR-CRS)[1]
- 2009 CDC launches the SUID Case Registry
- 2010 Active SUID surveillance began
- 2014 Two institutes at the National Institutes of Health – the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Neurological Disorders and Stroke (NINDS) funded an expansion of the SUID Case Registry by adding the SDY component to create the SUID and SDY Case Registry, allowing for surveillance of sudden death in infants and children up to age 20
    - During the planning period, a case definition, autopsy protocol, death investigation form and algorithm for case categorization were designed
- 2015 SDY data and sample collection began in funded states and jurisdictions[2]
    - First funding cycle (2015-2018): 10 SUID/SDY jurisdictions (8 SUID only jurisdictions)
    - Second funding cycle (2019-2023): 13 SUID/SDY jurisdictions (9 SUID only jurisdictions)
    - Third funding cycle (2024-2028): 12 SUID/SDY jurisdictions (20 SUID only jurisdictions)

## Public Health Data

- As of January 2025, the SUID and SDY Case Registry data includes comprehensive information on more than 12,000 cases (including 6,400 with SDY-specific variables and category data).
    - 11,170 of cases are sudden unexpected infant deaths
    - 1,546 of the cases are age 1 year or older

## DNA, Genomes and Phenotypes

- The SUID and SDY Case Registry currently has DNA samples consented for research from 450 cases*
    - 269 (65%) of these are already sequenced (whole genome sequencing data) and deposited in the NIH database of Genotypes and Phenotypes (dbGaP) at: Sudden Death in the Young Case Registry
    - At least 70 (16%) additional cases will be sequenced and deposited in dbGaP in 2025
    - There is phenotypic information on all cases consented for research, and de-identified autopsy reports are available for 186 (41%) of these cases

*The SUID and SDY Case Registry anticipates an additional 50 cases with DNA samples to be consented for research/per year

**Incidence Data**

NIH and CDC's SUID and SDY Case Registry provides important information about the characteristics of children who died suddenly and unexpectedly. Data is carefully compiled and thoroughly adjudicated. These are important first steps in trying to prevent sudden, unexpected death in the young. Case Registry data are **population-based** and thus do not rely solely on family, media, or even death certificate reporting of deaths. Based on the way data is compiled the Registry is able to provide a more accurate estimate of the mortality rate in the population. The Registry uses a to promote standardization in the characterization of SUID and SDY in real world settings, enabling tracking of trends, and facilitating comparability to other studies.

**SUID**

Sudden unexpected infant death (SUID) is a sudden and unexpected death of an infant less than 1 year of age and is often comprised of Sudden Infant Death Syndrome (SIDS), accidental suffocation or strangulation in bed, and other ill-defined causes. For these deaths, there is no obvious cause before investigation (About SUID and SIDS | SUID and SIDS | CDC). The vast majority of SUID are unexplained (82%)[4], occur during sleep (95%)[3], and are in an environment with multiple unsafe sleep factors (76%)[5]. A thorough death investigation, including an autopsy and detailed documentation of the sleep environment, is critical in determining the cause of death, as at least 18% are categorized as Explained - Suffocation with Unsafe Sleep Factors with a clear obstruction of the nose and mouth, neck or chest documented during the death scene investigation[4].

In 2020**,** the Case Registry issued a report[3] describing 1,132 cases of SDY (889 infants, 243 children up to age 18) from 9 states/jurisdictions. SDY occurred more often in infants, males, and Black infants/children. In two out of three deaths, a cause was not found after autopsy and investigation. In cases where a cause could be found, deaths were most often caused by suffocation in infants and lung and heart conditions in children.

**Infant SDY[3]**

- The SDY mortality rate among infants in 2015-2016 was 120/100,000 live births.
- The majority of SDY in infants was due to SUID (Sudden Unexplained Infant Death; 106/100,000 live births).
- Deaths peaked at 1 and 2 months of age.
- 70% of infant deaths were categorized as unexplained.
- Of the infant cases in which a cause could be identified, 22% were categorized as infant suffocation, 4% were categorized as respiratory deaths, 3% possible cardiac deaths, and 2% explained cardiac deaths.
- 95% of infant SDY occurred during sleep.
- There was wide geographic variation in the SUID mortality rate (39-161/100,000) in participating states/jurisdictions. Such geographic variation underscores the importance of including multiple large catchment areas when studying low frequency events like SDY.

**SDY in Children**[3]

- The rate of SDY among children in 2015-2016 was 1.9/100,000 infants and children.
- SDY rate was higher among males and Black children.
- The most common age groups for childhood SDY was 1 year (7/100,000 children) and 14-17 years (2.4/100,000 children).
- SDY in children ages 1 and older was more likely to be due to explained causes (57%) than unexplained causes (43%).
- Respiratory deaths made up 18% (0.3/100,000 children) and cardiac deaths made up 16% (0.3/100,000 children) of childhood SDY cases.
- The majority of SDY cases in children occurred at rest (0.8/100,000 children), rather than with activity (0.2/100,000 children).

**Sudden Cardiac Death in the Young (SCDY)** [3]

- The rate of SCDY in 2015-2016 was 2.7/100,000 live births among infants and 0.3/100,000 children among those 1-17 years.
- The SCDY rate in children is lower than reported in other studies. But we did not assume that "autopsy-negative" deaths were due to arrhythmia and therefore did not include autopsy-negative cases in the calculation of the SCDY mortality rate. Further research will help us to understand if "autopsy-negative" deaths are, in fact, due to arrhythmias. This approach is conservative, but it prevents misguided application of targeted prevention strategies to a population that is not yet well-defined.
- The leading cause of SCDY was myocarditis/endocarditis (45%).
- 3% of children had a known cardiac diagnosis prior to death.
- All diagnoses of hypertrophic cardiomyopathy (n=7) in this cohort were made postmortem.

**Sudden Unexpected Death in Epilepsy (SUDEP)** [3]

- The rate of pediatric SUDEP in 2015-2016 was 0.2/100,000 live births and children combined (higher than previously reported in children—0.11/100,000).
- Two-thirds of SUDEP cases occurred in those younger than 14 years of age.
- Most SUDEP cases occurred during sleep and were not witnessed.
- The use of active, population-based surveillance is an effective mechanism to identify SUDEP cases.

**SDY Due to Respiratory Causes**[3]

- The rate of SDY due to respiratory causes was 4.7/100,000 live births among infants and 0.3/100,000 children.
- 1/3 of respiratory deaths were attributed to asthma.
- Many of these asthma deaths were likely preventable. Increasing education on recognition of asthma exacerbations and optimizing access to care and treatment represent modifiable targets for SDY prevention strategies.

## Genomic Data

- Among infant cases analyzed with genome sequencing, there was a higher rate of potentially pathogenic variants in genes associated with epilepsy, especially Dravet syndrome, and a lower rate of pathogenic variants in cardiac genes (4%)[6].
- If using diagnostic genetic testing as part of the autopsy, a panel that includes both cardiac and epilepsy genes should be ordered.

## Best Practices

### Bereavement Support

All SUID and SDY families that suffer a death deserve the opportunity to utilize bereavement services. Integration of these services into Medical Examiner and Coroner (MEC) offices is an ideal setting for providing these services. This model reduces barriers to accessing care and can serve as the initial point of contact for families while providing emotional support. This has been a successful model at one of the SUID and SDY Case Registry sites: the Philadelphia Medical Examiner's Office.

### Family Medical Referral

Despite existing guidelines, at-risk family members are not being referred for follow-up medical screening on a routine basis[7].

### Family Medical History at Time of Investigation[8]

The two most important questions for death investigators to ask a family at the time of the death investigation are:

1. Is there any family history of sudden death < 50 years of age? If yes, who and what happened?
2. Is there any family history of heart disease < 50 years of age? If yes, who and what was the diagnosis?

### Suggested Processes for obtaining consent for Genomic Research[9]

- Involve staff from medical examiner offices in developing and maintaining consent process
- Every family should be offered bereavement support, first and foremost
- Accurate contact information (cell phone and email) should be collected by the death investigator and shared with the person attempting consent
- Persons attempting consent should be comfortable and confident talking to grieving families
- Utilize a death investigator or someone else from the death investigation team or support staff (bereavement specialist or social worker) already interacting with the family to attempt consent
- Attempts to contact for consent should be made early and often

## Funding

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CDC Contract with Data Coordinating Center: 75D30123C16275
NIH Contract with the Data Coordinating Center for consent and biospecimen-related activities: 75N92024C00001

## References


1. **The Sudden Unexpected Infant Death Case Registry: A Method to Improve Surveillance**

   Shapiro-Mendoza CK, Camperlengo LT, Kim SY, Covington T. The sudden unexpected infant death case registry: a method to improve surveillance. Pediatrics. 2012 Feb;129(2):e486-93. doi: 10.1542/peds.2011-0854. Epub 2012 Jan 9. PMID: 22232303.

2. **The Sudden Death in the Young Case Registry: Collaborating to Understand and Reduce Mortality**

   Burns, K.M., Bienemann, L., Camperlengo, L., Cottengim, C., Covington, T.M., Dykstra, H., Faulkner, M., Kobau, R., Erck Lambert, A.B., MacLeod, H., Parks, S.E., Rosenberg, E., Russell, M.W., Shapiro-Mendoza, C.K., Shaw, E., Tian, N., Whittemore, V., Kaltman, J.R. (2017). The Sudden Death in the Young Case Registry: Collaborating to Understand and Reduce Mortality. Pediatrics, 139(3).

3. **Epidemiology of Sudden Death in a Population-Based Study of Infants and Children**

   Burns KM, Cottengim C, Dykstra H, Faulkner M, Erck Lambert AB, MacLeod H, Novak A, Parks SE, Russell MW, Shapiro-Mendoza CK, Shaw E, Tian N, Whittemore V, Kaltman JR. (2020). Epidemiology of Sudden Death in a Population-Based Study of Infants and Children. Journal of Pediatrics: X, 100023

4. **Explaining Sudden Unexpected Infant Deaths, 2011-2017**

   Parks SE, Erck Lambert AB, Hauck FR, Cottengim CR, Faulkner M, Shapiro-Mendoza CK. Explaining Sudden Unexpected Infant Deaths, 2011-2017. Pediatrics. 2021 May;147(5):e2020035873. doi: 10.1542/peds.2020-035873. PMID: 33906930; PMCID: PMC8132195.

5. **Characteristics of Sudden Unexpected Infant Deaths on Shared and Nonshared Sleep Surfaces**

   Erck Lambert AB, Shapiro-Mendoza CK, Parks SE, Cottengim C, Faulkner M, Hauck FR. Characteristics of Sudden Unexpected Infant Deaths on Shared and Nonshared Sleep Surfaces. Pediatrics. 2024 Mar 1;153(3):e2023061984. doi: 10.1542/peds.2023-061984. PMID: 38374785.

6. **The Impact of Damaging Epilepsy And Cardiac Genetic Variant Burden In Sudden Death In The Young**

   Puckelwartz MJ, Pesce LL, Hernandez EJ, Webster G, Dellefave-Castillo LM, Russell MW, Geisler SS, Kearns SD, Karthik F, Etheridge SP, Monroe TO, Pottinger TD, Kannankeril PJ, Shoemaker MB, Fountain D, Roden DM, Faulkner M, MacLeod HM, Burns KM, Yandell M, Tristani-Firouzi M, George AL Jr, McNally EM. The impact of damaging epilepsy and cardiac genetic variant burden in sudden death in the young. Genome Med. 2024 Jan 16;16(1):13. doi: 10.1186/s13073-024-01284-w. PMID: 38229148; PMCID: PMC10792876.

7. **Family Screening After Sudden Death in a Population-Based Study of Children**

   Kannankeril PJ, Shoemaker M.B, Fountain D, Roden D.M, Yandel M, Tristani-Firouzi, M, Etheridge, S.P, Webster, G, George A. L, McNally, E. M, MacLeod, H, and Burns, K.B. Family Screening After Sudden Death in a Population-Based Study of Children. Pediatrics. 2022;149(4):e2021054432

8. **Barriers to Family History Collection and Family Medical Screening Recommendation in the Sudden Death in the Young Case Registry**

   Machek, B, Buck, C, MacLeod, H and Keywan, C. Barriers to Family History Collection and Family Medical Screening Recommendation in the Sudden Death in the Young Case Registry. Am J Forensic Med Pathol 2025; 46:01

9. **What Has the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry Learned About Consenting Families for DNA Banking and/or Genomic Research?**

   MacLeod, H, Buczkowski, E, Faulkner, M, Felzke, K and Burns, K. What Has the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry Learned About Consenting Families for DNA Banking and/or Genomic Research? Am J Forensic Med Pathol 2024;00: 00–00